

**Post Treatment for Prostate Cancer: The Experiences and
Psychosocial Needs of Black African and Black Caribbean Men and
their Partners**

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ABSTRACT

This study explored the experiences, psychosocial needs and how best to address them after prostate cancer treatment for Black African/Black Caribbean men and their partners in England. Cancer statistics in the United Kingdom show that Black African and Black Caribbean men have a disproportionately higher risk (1 in 4) of developing prostate cancer earlier in life and in more aggressive forms compared with Caucasian (1 in 8) and Asian (1 in 13) men. An intersection between their higher prostate cancer risk, long term treatment side effects and their ethnic cultural context suggests that Black African/Black Caribbean men and their partners may have unique experiences and support needs after prostate cancer treatment. However, these phenomena are currently not well understood.

Using constructivist grounded theory methodology, thirty one face-to-face, five Skype and two telephone interviews were conducted with twenty five men, eleven partners and two healthcare professionals recruited in England. Two focus groups were also held with an additional nine healthcare professionals at their respective Trusts. Data were analysed using constant comparison. Charmaz's key stages of initial, focused and theoretical coding were followed. Theoretical coding of key categories from the three data sets culminated in the development of a substantive theory 'man in the driving seat' which articulates the patterns of behaviour of Black African/Black Caribbean men and their partners along the prostate cancer journey.

Findings showed that gender-based cultural values and norms influenced how men and partners responded and coped with treatment side effects of prostate cancer. There were indications that the men were in the 'driving seat' whilst their partners seemed to be placed in the 'passenger seat' along the prostate cancer journey. Triangulating participants' data showed that

most of their experiences resonate with literature on Caucasian groups. However, some important cultural differences were observed in the experiences of men and partners in this study especially in the areas of disclosure, partner engagement, coping, accessing support and enacting their masculinity roles.

Culturally-informed gender roles and identities should be considered when developing post-treatment support for Black African/Black Caribbean men with prostate cancer and their partners. Whilst these men may not spontaneously admit their need for help, healthcare professionals need to explore their professional expertise to navigate cultural barriers and identify, treat and manage post-treatment psychological distress among these men. It is essential to also recognise partners' support needs and incorporate these within the psychosocial support agenda. Inclusive and culturally sensitive psychosocial support which particularly recognises the experiences and needs of men and their partners and supports them both as individuals and as a couple is recommended.

Key words: Black African, Black Caribbean, men, partners, prostate cancer, psychosocial, experiences, grounded theory.

ABBREVIATIONS

AA	African American
ACS	American Cancer Society
BA	Black African
BC	Black Caribbean
BME	Black and Minority Ethnic
CaP	Prostate Cancer
CGT	Constructivist Grounded theory
CRUK	Cancer Research UK
DRE	Digital Rectal Examination
HBM	Health Belief Model
HCPs	Healthcare Professionals
HRA	Health Research Authority
IOM	International Organisation for Migration
IPA	Interpretative Phenomenological Analysis
MRI	Magnetic Resonance Imaging
NHS	National Health Service
NICE	National Institute for Health and Care Excellence
NISRA	Northern Ireland Statistics and Research Agency
ONS	Office of National Statistics
PAHO	Pan American Health Organisation
PCUK	Prostate Cancer UK
PPI	Patient and Public Involvement

PSA	Prostate Specific Antigen
UK	United Kingdom
UREC	Ulster University Research Ethics Committee
US	United States
WAS	World Association for Sexology
WHO	World Health Organisation

DECLARATION

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LIST OF PUBLICATIONS AND STATEMENTS INDICATING THE PHD STUDENT'S CONTRIBUTIONS

Paper 1 (Published)

Bamidele, O., McGarvey, H., Lagan, BM., Ali. N., Chinegwundoh, F., Parahoo, K. and McCaughan, E. (2017) Life after prostate cancer: a systematic literature review and thematic synthesis of the post-treatment experiences of Black African and Black Caribbean men.

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PhD Student's contribution: First and corresponding author, drafted and compiled the manuscript, developed search strategy, conducted search, critically appraised selected studies, identified and synthesised themes, revised manuscript based on co-authors' comments and submitted to journal, revised the manuscript for re-submission to journal, managed the review process.

Paper 2 (Published)

Bamidele, O., McGarvey, H., Lagan, BM., Ali. N., Chinegwundoh, F., and McCaughan, E. (2018) "Hard to reach, but not out of reach": barriers and facilitators to recruiting Black African and Black Caribbean men with prostate cancer and their partners into qualitative research.

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application process, recruited participants and conducted their interviews, revised manuscript based on co-authors' comments, submitted manuscript to journal, revised manuscript for re-submission to journal, managed the submission process.

Paper 3 (Published)

Bamidele, O., Lagan, BM., McGarvey, H., Wittmann, D and McCaughan, E. (2018) “...*It might not have occurred to him that this woman that is taking care of me has some emotional needs as well...*”: The Unheard Voices of Wives of Black African and Black Caribbean Men with Prostate Cancer. *Journal of Supportive Care in cancer* DOI: 10.1007/s00520-018-4398-4

PhD Student's contribution: First and corresponding author, co-developed the study with supervisory team, drafted and compiled the manuscript, developed methodology, recruited participants and conducted data collection and analysis, revised manuscript based on co-authors' comments, submitted manuscript to journal, revised manuscript and resubmitted to journal, managed the submission process.

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GLOSSARY OF TERMS

Active surveillance:	Delaying radical treatment but monitoring the cancer progression
Basic social processes:	Patterns of behaviour
Brachytherapy:	Implantation of radioactive seeds
Data contamination:	Influence of preconceived ideas on developing theory
Haematuria:	Blood in urine
Pro-inflammatory cytokines:	Inflammation-promoting proteins produced by certain cells in the body which often worsen disease conditions by subduing antibodies and limiting certain body functions
Prostate:	A walnut-sized reproductive organ found beneath men's bladder and around the urethra
Prostatectomy:	Removal of the prostate gland through surgery
Protective buffering:	Not sharing information with others in order to protect them from possible distress
Psychosocial:	Psychological, emotional and social aspects of health
Radiotherapy:	Use of external beam radiations to treat cancer
Retrograde ejaculations:	Redirection of semen to the urinary bladder

Snowballing:	Identifying potential participants through referral by those who have already been recruited into the study
Theoretical sampling:	Data collection directed by emerging categories from preliminary interviews
Theoretical saturation:	Conceptual understanding of theory and no further data is required
Theoretical sensitivity:	Rigorous and unbiased interpretation of the data until theory is fully conceptualised

Note: Within text ^g refers to terms defined in glossary.

CHAPTER ONE: INTRODUCTION

1.1 Introduction and study context

Black African (BA) and Black Caribbean (BC) men in the United Kingdom (UK) have disproportionately higher risk (1 in 4) of developing prostate cancer (CaP) at a younger age and more aggressive form compared with Caucasian (1 in 8) and Asian (1 in 13) men (Lloyd *et al.* 2015; Prostate Cancer UK [PCUK] 2016). Evidence is inconclusive regarding the reasons for this disparity in CaP risk but there are postulations that complex intersections between genetics, ethnicity and socio-cultural environment are key contributing factors (Thakare and Chinegwundoh 2015). Their higher risk of CaP also suggests that BA and BC men may be prone to more complicated treatment procedures as disease stage at diagnosis and patient age are key considerations when making treatment recommendations for the disease (National Institute for Health and Care Excellence [NICE] 2014).

Survival rates from CaP have continued to improve in the UK and many men now live up to five years or more after diagnosis (Cancer Research UK [CRUK] 2016). However, there are severe treatment-related side effects such as sexual dysfunction, incontinence issues, fatigue and hot flashes which substantially affect the daily lives and psychosocial well-being of affected men and also impact on their partners (McCaughan *et al.* 2015). Evidence also highlights strong correlations between treatment type and the degree of resulting side effects (van Tol-Geerdink *et al.* 2013). These may have more adverse implications for the psychosocial health of BA and BC men due to their higher risks of CaP. There are also suggestions from current literature that improved survival rates from CaP (in the absence of co-morbidities) often influence the transition in men's priority concerns from cancer fatality to their quality of life after treatment

(Dickey and Ogunsanya 2018). This may be because for most men (and their partners), the reality of being diagnosed with CaP often sets in when they are experiencing treatment side effects and they may be compelled to make substantial changes to their usual activities and daily routines (Bowen 2016). With the disproportionately higher risk of aggressive CaP among younger BA and BC men, the psychosocial consequences of treatment side effects may be even more difficult for them and their partners to deal with (Desantis *et al.* 2014).

Whereas similarities may exist in men's experiences of the physical side effects of CaP treatment irrespective of their ethnic orientation (Corona *et al.* 2012; Larkin *et al.* 2014), evidence suggests that cultural disparities are apparent in how they respond, adapt and cope with such side effects (Bamidele *et al.* 2017a). The impact of CaP on the man's partner and on a couple's marital relationship (Wittmann *et al.* 2015) also suggests that men treated for the disease and their partners may experience substantial psychosocial burden and therefore should be supported in a culturally sensitive way (Harandi *et al.* 2017).

Among BA and BC groups, predominant perceptions of stigma associated with CaP (Mulugeta *et al.* 2017), coupled with traditional gender values and hierarchical power structure in marital relationships (underpinned by patriarchy) (Kolawole *et al.* 2012) suggest their psychosocial support needs after CaP treatment may be different. However, these phenomena have been underexplored for BA and BC groups as they are underrepresented in current psychosocial research on CaP survivors, especially within UK-based literature. This study aimed to address this gap in the evidence base. Using constructivist grounded theory design, this PhD study explored the experiences, psychosocial needs and how to address them after CaP treatment for BA/BC men and their partners resident in England. The subsequent sections of this chapter

discuss: the rationale for the study; demographic characteristics of BA and BC populations; and the organisation and structure of the entire thesis.

1.2 Rationale

The National Health Service (NHS) England has set out in its recent '*NHS five year forward*' agenda, a priority to actively engage with patients (especially 'hard to reach' groups with poorer health outcomes) to identify and address their healthcare needs in a sensitive manner (NHS England 2017a). NICE also recommends that clinical treatment aids be complemented with psychosocial support in order to promote a more holistic recovery and improved quality of life among men with CaP (NICE 2015). In order to achieve these objectives, there is need to take into account the existing ethnic disparities in risks of developing CaP, disease outcomes and post- treatment experiences (Koffman *et al.* 2008; Wooten *et al.* 2014; McCaughan *et al.* 2015). However, the majority of current psychosocial research on men with CaP and their partners has predominantly focused on Caucasian populations (Tanner *et al.* 2011; Forbat *et al.* 2012; O'Shaughnessy *et al.* 2013; Wittmann *et al.* 2014; McCaughan *et al.* 2015; Speer *et al.* 2017). The dearth of research involving higher risk BA and BC men and their partners suggests that their psychosocial experiences and specific support needs are not sufficiently understood to inform culturally sensitive psychosocial support for them after CaP treatment.

Within the limited research on CaP and Black men in the United States (US) and the UK, the majority has focused either on epidemiological aspects of CaP (Jemal *et al.* 2010; Rebbeck *et al.* 2013; Jones and Chinegwundoh 2014) or, on the men's knowledge, attitudes and beliefs regarding CaP and prostate screening (Odedina *et al.* 2011; Pedersen *et al.* 2012; Brown 2014; Mulugeta 2014; Machirori *et al.* 2018). Reports from these studies indicate that ethnicity and

culture play dominant roles in the men's risk of CaP, and also influence their perceptions and help-seeking behaviour towards the disease. Specifically within the BA and BC cultural contexts, evidence reports that perceptions of fear (of pain and death), stigma, invasion of personal privacy and 'punishment from God' are often associated with cancer and a cancer diagnosis (Bamidele *et al.* 2017b). In addition to these beliefs about cancer, perceptions that CaP makes a man effeminate and significantly upsets core masculine values (for example, sexual virility, prowess and breadwinning) (Fergus *et al.* 2002; Mulugeta 2014) have been identified as contributing to delays in seeking help for CaP diagnosis and treatment by BA and BC men (Pedersen *et al.* 2012; Mulugeta 2014). The role of cultural values and beliefs in influencing the post-treatment experiences and perceptions of psychosocial support within the BA/BC cultural context is currently under-explored.

Few CaP studies have investigated the psychosocial experiences after treatment among Black men (Purnell *et al.* 2011; Bowen 2016; Imm *et al.* 2017), their partners (Rivers *et al.* 2011) or couples (Rivers *et al.* 2012) but these studies are mostly US-based and focused on African American (AA) groups. Disparities in demographic and socio-cultural settings between the US and the UK indicate that evidence from studies on AA groups may not totally reflect the experiences of UK-based BA and BC populations. For example, studies (Jones *et al.* 2011; Xanthos *et al.* 2010; Williams *et al.* 2014) have identified lack of insurance and financial challenges pose as barriers to the uptake of healthcare services by AA men and further contribute towards their increased psychological distress after CaP treatment compared with Caucasian men. Given that healthcare services (including prescriptions and long-term care for people with cancer) are largely subsidised or free in the UK compared with the US (Schoen *et al.* 2009), what

constitute the psychological concerns of UK-based BA/BC men treated for CaP may go beyond the financial implications of healthcare cost.

In order to achieve healthcare priority to reduce inequalities in cancer experiences and outcomes through person-centred care (NICE 2014), it is also necessary to recognise and take into account the cultural diversity of the UK population which has been advanced by increasing migration and globalisation (Office for National Statistics [ONS] 2012). The dynamic nature of migration suggests that Black and Minority Ethnic (BME) groups may be marginalised in healthcare and this may further broaden the gap in health experiences and outcomes between them and the majority population (Bhopal 2006; Helman 2007). For example, BME groups have been reported to record less satisfying experiences of healthcare (Thomas *et al.* 2009; Pinder *et al.* 2016) and lower access and utilisation of cancer services compared with the majority population (Daher 2012). Evidence suggests that knowledge gaps regarding their specific needs to inform content and delivery of culturally sensitive healthcare (Das-Munshi *et al.* 2012; Pinder *et al.* 2016) may have also contributed toward these inequalities. For BA/BC men with CaP and their partners in the UK, it is unclear what factors contribute towards their post-treatment healthcare experiences or why they are underrepresented in current psychosocial support for CaP survivors.

Findings from a systematic review by Chambers *et al.* (2011) which focused on psychosocial interventions for men and partners after CaP treatment identified only one study on Black men and their partners. This study (Campbell *et al.* 2007) was conducted in the US with AA men. Further data on AA populations (Xanthos *et al.* 2010) also suggest that historical experiences of racial discrimination which dates back to the era of slavery, coupled with the failed Tuskegee syphilis trial (Jones *et al.* 2009; Centers for Disease Control and Prevention

[CDC] 2017) contributed towards their reduced access and utilisation of healthcare services as they expressed perceptions of mistrust in the healthcare system. Such racial discrimination may not be as widely reported in the present day UK due to globalisation (ONS 2012) and advancing equality and diversity regulations (Sharma 2016). However, ethnic stereotyping, cultural barriers in patient-provider interactions and lack of trust in the healthcare system have been reported to contribute to perceptions of negative healthcare experiences among Black men in the UK (Pedersen *et al.* 2012). Considering the growing recognition of the therapeutic value of post-treatment healthcare and psychosocial support in promoting improved quality of life among men with CaP and their partners (Harandi *et al.* 2017), the importance of cultural competence and sensitivity in developing and delivering such support cannot be overemphasised. Such cultural competence and sensitivity can be enhanced by engaging with users of support services to elicit their perspectives on what they need and how to address them in a way that services will be acceptable and utilised by them (Hayes *et al.* 2012). This could also help to reduce existing inequalities in the psychosocial experiences and support needs of an ethnically diverse cohort of survivors of CaP and their partners in the UK.

In light of the aforementioned rationale, this study was considered important as it has the potential to address the current gap in the evidence base and extend the literature in this research area. The specific aims and objectives of this study are presented after a more detailed literature review in Chapter Two (see section 2.8). To better understand the study sample, their demographic characteristics are discussed next.

1.3 Black African and Black Caribbean men in the United Kingdom: who are they?

Since the Second World War, ethnic diversity has increased in the UK due to migration from across the world especially from Asia, Africa and the Caribbean (ONS 2012). The last few decades have also witnessed an increased migration of BA and BC populations into the UK from 2% in 2001 to 3.3% of the total UK's population in 2011 (ONS 2015). BA men have been identified as those who have their ancestral roots in Africa and self-identify or are identified as Africans (excluding those from North and South African countries) (Bhopal 2004). BC men are also of African ancestry but have settled in the Caribbean and self-identify or are identified as African Caribbean (Bhopal 2004). Although BA and BC men are related by the same African origin, they emigrated from different West African (Nigeria, Ghana, Zimbabwe, Malawi, Zambia, Kenya, Cameroun, Sierra Leone, Somalia) and Caribbean (Jamaica, West Indies, Guyana, Trinidad & Tobago, Barbados) countries respectively (ONS 2012). Dating back to the transatlantic slave trade which occurred between the fifteenth and nineteenth centuries when BC men were transported from coastal areas of West Africa to do plantation work for slave traders in the Caribbean, it has been concluded that BA and BC men share similar genetic make-up which has been used to explain their comparable high CaP risks (Ben-Shlomo *et al.* 2008). Christianity and Islam are the most commonly practised religions within the BA and BC communities (Brown 2014).

Statistics from the 2011 census reported that the BA population were the largest Black population in the UK and they are mostly resident in England (ONS 2015). Those who originate from Nigeria are the largest members of the BA community (ONS 2015). The migration journey of BAs into the UK has mostly been attributed to: everyday migration changes; socio-economic reasons; desire for access to quality education and better training opportunities; and seeking

asylum due to political instability in their originating countries (Brown 2014). BC populations account for less than 1% of the total UK population and their immigration journey dates back to the 1940s and early 1950s when the historic ship ‘Windrush’ conveyed the first generation immigrants to England in 1948 (Campbell and McLean 2002; Brown 2014). The mass migration of people from the Caribbean was prompted by the global recruitment of skilled workforce by the British government across the Caribbean, Africa and South East Asia, as part of its nation rebuilding effort (Brown 2014). Reports show those from Jamaica form the largest group within the BC community and are mostly resident in England (ONS 2015).

Even though BA and BC men originate from different West African and Caribbean countries, a study by Mulugeta (2014) demonstrated that in addition to similarities in their African heritage and racial colour as Black, similarities also exist in their cultural views and attitudes towards cancer and these have been shown to influence their pre-and post-treatment outcomes. In a systematic review of 33 studies, Pedersen *et al* (2012) sought to examine the knowledge and perceptions of CaP among BA and BC men. Their review identified personal and socio-cultural factors as important determinants of BA and BC men’s help-seeking regarding CaP as men perceived diagnostic tests (for example, digital rectal examination [DRE]) and treatment for the disease as a substantial threat to their masculinity. Lack of trust in healthcare professionals and the healthcare system which was reportedly aggravated by lack of effective patient-provider communication also deterred many participants in the original studies from seeking necessary help for CaP diagnosis (Pedersen *et al.* 2012). Whilst this review provided useful insights into factors which influence the help-seeking behaviour of BA and BC men towards prompt diagnosis of CaP, there is need for further research which focuses on their experiences of living with side effects of CaP treatment. Research which explored the

perceptions of psychosocial support after CaP treatment is also needed for high risk BA and BC groups.

1.3.1 Partners of Black African and Black Caribbean men with prostate cancer

Partners (a significant other in marital or intimate relationship) have been shown to play a central role in men's CaP journey by providing physical, emotional and practical support care through the diagnosis, treatment and post-treatment phases (Harden *et al.* 2006; Tanner *et al.* 2011). Evidence highlights that men with partners experience better outcomes and higher survival rates from CaP than those without partners (Kazer *et al.* 2011; Wittmann *et al.* 2014). Research data on partners of Caucasian men with CaP shows that partners themselves experience significant psychosocial distress post-treatment (Nelson and Kenowitz 2013) due to less satisfying marital relations, communication gaps and care-giving burdens associated with CaP treatment. In surveying the literature, it was identified there has been little attention paid to investigating the personal experiences and specific support needs of partners within higher risk BA and BC populations.

1.4 Organisation and structure of the thesis

This study is presented using the thesis by papers format. The thesis is presented in five chapters which are outlined in Table 1:

Table 1: Organisation of Thesis by Chapter

CHAPTER	TITLE	CHAPTER CONTENT
1	Introduction	Presents an introduction to the thesis and focuses on the rationale, demographic characteristics of the study sample and organisation and structure of the thesis.
2	Literature review	Features the literature review and critical appraisal of previous research in this area in order to identify existing gaps for the

		current study to fill. The chapter starts with a detailed background into the study. This is followed by a discussion of key concepts and relevant theories to provide a background insight into the relevance and importance of the study. The chapter ends with a summary of key findings from the published review (Paper 1) and the aims and objectives of this study. The gaps in the literature in addition to the rationale discussed in Chapter One, informed the study's aims and objectives. The published review paper is included at the end of section 2.6.
3	Methodology	Provides a comprehensive description of the research methodology. The chapter starts with a discussion of the researcher's philosophical assumptions. The research design and the rationale for choosing constructivist grounded theory approach are discussed next. Subsequent parts of the chapter discuss sampling, data collection, data analysis and ethical considerations. A detailed discussion of how participants were identified and recruited into the study and the barriers and facilitators to recruiting 'hard to reach' BA/BC men with CaP and their partners have been written up as a paper and published (Paper 2). The paper is included at the end of section 3.3. The chapter ends with a discussion on how rigour and trustworthiness were ensured in this study.
4	Findings	This chapter reports study findings and is presented in two parts. The first part reports the men's and HCPs' data. Partners' data is fully reported as a published paper (Paper 3) and is included at the end of section 4.4. In order to enhance the narrative flow of overall study findings, a summary of partners' data is also included in this chapter. The second part of the chapter presents the theory developed in the study.
5	Discussion and Conclusion	The final chapter details an analytical discussion of study findings and is presented in three main sections. The first section discusses key findings which emerged from the men's, partners' (Paper 3) and HCPs' data. The second section discusses the substantive theory developed in the study. The third and final section discusses the implications for practice, recommendations and the strengths and limitations of the study. The study's contributions to knowledge and directions for future research are also identified. The chapter ends with the conclusion.

1.5 Summary

This chapter has provided the context for the study and focused on the rationale for conducting this research. The demographic characteristics of the study sample and thesis outline were also discussed. A detailed discussion of relevant background literature to identify gaps which informed the study's aims and objectives is presented next in Chapter Two.

CHAPTER TWO: LITERATURE REVIEW

2.1 Introduction

This chapter discusses the literature reviewed for the study and is presented in two parts. The first part broadly discusses background literature, key concepts and some relevant theories to help understand the importance and potential usefulness of this study. The second part presents a more focused systematic literature review which synthesised core studies on the post -treatment experiences of BA and BC men with CaP and identified gap areas which informed the specific aims and objectives of the current study. The systematic literature review has been published (**Paper 1**) and is included at section 2.6 in this chapter.

2.2 Reviewing the literature prior to conducting a grounded theory study

Debates relating to the role of literature reviews in grounded theory have moved beyond the ‘if’ and ‘why’ literature should be reviewed. The importance of situating the current research within existing body of knowledge has now been widely acknowledged (Bryant and Charmaz 2007; McGhee *et al.* 2007; Dunne 2011). Rather, existing debates have continued to focus on ‘when’ and ‘how’ the literature should be used in grounded theory research (McGhee *et al.* 2007; Dunne 2011). Classical grounded theorists (for example, Glaser and Strauss 1967) advocate for delayed review of the literature in order to ensure that the emerging theory is allowed to naturally develop from primary data analysis and avoid ‘data contamination^g’. However, other grounded theorists (for example, Bryant and Charmaz 2007; Strauss and Corbin 2008) argue that an early literature review could: help trigger research questions, provide necessary rationale for conducting the research as required by ethics reviewers, avoid methodological errors made by previous studies, guide theoretical sampling^g, and promote theoretical sensitivity^g. Charmaz

(2014) also reiterates that a preliminary literature review is necessary to enable the researcher to come to the research with an ‘open mind’ (through reflexivity) not a ‘blank head’. The researcher conceded with these later views and conducted an early literature review for the reasons highlighted above as well as to rationalise how the current research would be extending the literature and make a new contribution to knowledge as this is an essential requirement for a PhD study. Detail on how ‘data contamination’ (as aforementioned by Glaser and Strauss [1967]) was avoided is provided in Chapter Three, section 3.4. As advised by Charmaz (2014), a second in-depth literature review was conducted after data analysis to help strengthen the researcher’s argument on how the current research extends the literature and makes new contribution to knowledge.

2.3 Background literature

2.3.1 Prostate cancer: global trends and epidemiological overview

CaP usually results from an uncontrolled replication of cells around the prostate^g gland causing tumours which could spread to other parts of the body and endanger life if not promptly curtailed (PCUK 2017). Although the cause of CaP remains unknown, genetics, age and ethnicity have been recognised as the most significant risk factors (CRUK 2015). Amidst these factors, men who have a family history of prostate or breast cancer, those aged over 65 years and men of African and Caribbean ethnic origins are reported to have an increased risk of developing CaP compared with the general population (NICE 2015; CRUK 2015).

Globally, CaP is ranked as the leading cause of male cancer deaths and it affected over 1.11 million men worldwide in 2012 (CRUK 2016). A global estimate of cancer prevalence by Bray *et al* (2013) also reported CaP as the most occurring male cancer in about 111 countries

with greater incidence in major continents like the US, Europe and Sub-Sahara Africa. An earlier study by Jemal *et al* (2010) also reported highest occurrences of CaP in North America, Oceania and Europe with lowest incidence in Asia. The high prevalence of CaP in these regions has been partly attributed to increased access to the prostate specific antigen (PSA) testing which has also been implicated in cases of over-diagnosis of the disease (Jemal *et al.* 2010). Although there has been a decrease in the incidence of CaP in the US, Canada and Australia over the last two decades, its incidence has continued to increase in the UK and some other parts of Europe as access to PSA testing advances in these areas (Baade *et al.* 2009).

In the UK, CaP is the most common male cancer and it accounts for about 26% of all cancer diagnoses among men (CRUK 2016). There are postulations that about one out of every eight Caucasian men in the UK is at risk of developing CaP at some point in their lifetime and this risk is doubled for BA and BC men (1 in 4) (PCUK 2016). Further projections suggest a considerable rise in the prevalence of CaP across the UK from 835 per 100,000 in year 2010 to 2306 per 100,000 by year 2040 (Maddams *et al.* 2012). The projected rise in the prevalence of CaP has been attributed to improving access to early diagnosis, improvements in treatment procedures and a growing population (De Sousa *et al.* 2012; PCUK 2017). This infer there may also be a rise in the psychosocial burden of CaP survivors due to inevitable post-treatment side effects, especially among higher risk BA and BC populations. The potential implications of the increasing prevalence of CaP on men and their partners' quality of life also highlight the criticality of providing appropriately tailored psychosocial support to address their specific needs irrespective of their social or cultural differences.

With regards to symptoms of CaP, some men may not present any at diagnosis especially if the CaP is localised and in its early stage (PCUK 2017). Other men may experience symptoms

which could range from mild to severe urinary difficulties, frequent urination, blood stained urine or semen, lower back or pelvic and hip pain (PCUK 2017). Poor knowledge of symptoms of CaP has been shown to also contribute towards delayed diagnosis of the disease among BA and BC men (Pedersen *et al.* 2012). Late diagnosis may lead to more intensive treatment procedures and consequently poorer post-treatment outcomes (NICE 2014).

Diagnostic procedures for CaP usually start with the Prostate Specific Antigen (PSA) test (blood test) which has emerged as the most common diagnostic procedure in investigation for CaP. Following observed limitations in the PSA test and ongoing controversies regarding its sensitivity and specificity (Roth *et al.* 2008; Odedina *et al.* 2011), the DRE was introduced as an additional diagnostic measure to facilitate a more accurate diagnosis of CaP (Walsh *et al.* 2014). A DRE usually involves the insertion of a gloved finger by the doctor into the patient's rectum in order to examine the prostate gland and check for abnormalities (CRUK 2014). Evidence shows that many BA and BC men are culturally averse to the DRE procedure as they often report it as degrading, embarrassing, painful and synonymous with homosexual activity which is considered a threat to their sexuality (Seymour-Smith *et al.* 2016) and masculine ideals (Ocho and Green 2013). Other confirmatory tests to confirm a diagnosis of CaP include biopsies, rectal ultrasound and a magnetic resonance imaging (MRI) scan (CRUK 2014).

Currently, there is no 'gold standard' treatment for CaP, but NICE guidelines recommend either active surveillance (watchful waiting) or radical treatment depending on disease stage and risk of spreading to other parts of the body (NICE 2015). Radical treatment for early stage CaP usually involves prostatectomy^g, brachytherapy^g and radiotherapy^g (CRUK 2014). For more advanced cases, hormone therapy is often recommended either as a single treatment or in combination with either of the afore-mentioned radical treatment options (NICE 2014). Active

surveillance^g may be recommended for older men with non-aggressive CaP (O’Callaghan *et al.* 2014)

2.3.2 Psychosocial impact of prostate cancer

As previously mentioned (Section 1.1), treatment for CaP comes with unfavourable side effects which not only limit men’s physical functioning but also impacts on their psychosocial^g health and that of their partners (McCaughan *et al.* 2013; Sharpley *et al.* 2014a; Chambers *et al.* 2015). This has become an important public health concern. Gavin *et al.* (2015) conducted a quantitative study involving 3,348 patients recruited from Northern Ireland and the Republic of Ireland. Findings showed that all their respondents, most of whom were diagnosed before the age of 65 years and had undergone radical treatment, experienced at least one (90%), three (61%) or four (20%) side effects of CaP treatment respectively. Respondents experienced varying degrees of erectile dysfunction (68%), libido loss (58%) and fatigue (55%) depending on treatment option received (Gavin *et al.* 2015). Findings from wider related studies also reveal a similar trend in men’s experiences of sexual problems (Resnick *et al.* 2013; DeSantis *et al.* 2014), incontinence issues (van Tol-Geerdink *et al.* 2013), fatigue (Larkin *et al.* 2014) and ‘menopause-like’ symptoms (for example, weight gain and hot flashes) (Corona *et al.* 2012) following CaP treatment. These treatment side effects have also been reported to significantly impact on men’s personal and social perceptions of their masculinity (Maliski *et al.* 2008; O’Shaughnessy *et al.* 2013; McCaughan *et al.* 2015). The psychosocial impact of each of the three most common treatment side effects (that is, sexual dysfunction, urine incontinence and fatigue) are now discussed.

2.3.2.1 Sexual dysfunction

Sexual dysfunction following treatment for CaP has been linked to feelings of psychological and emotional distress (Casey *et al.* 2012; Benedict *et al.* 2014) and affects between 33% to 98% of CaP survivors (Sanders *et al.* 2006; Badr and Taylor 2009). Post-treatment sexual dysfunction includes: a reduced or total loss of sexual desire, inability to achieve or sustain an erection (erectile dysfunction), impotence, dry orgasms and unsatisfying sexual experiences. Besides altering men's perception of their masculine identity, evidence suggest that sexual dysfunction following treatment for CaP could further have unfavourable consequences on marital relationships especially where there had been a satisfying sexual relationship between a man and his partner prior to diagnosis (Gannon *et al.* 2010). This may be due to the common perception of sex as an important means of sharing erotic love and deep emotional feelings between couples in which sexual activity forms part of most couples' normal lives (Gannon *et al.* 2010). Previous research (Lindau *et al.* 2007; Laumann and Waite 2008) also shows that many men still maintain interest in sexual activities well into their old age and consider penetrative sex as an integral part of their masculine identity. Hence, a disruption in spontaneous erections and sexual abilities could make some men withdraw from intimate contact which may then result in adverse psychosocial consequences such as communication breakdown, depression and low self-esteem among such men and their partners (Roth *et al.* 2008; Nelson and Kenowitz 2013).

A recent phenomenological study by Schantz (2016) investigated the psychosocial impact of sexual dysfunction on men post-surgery for CaP. Findings from the four men who were conveniently sampled through a sexological counselling service in a Danish university hospital and interviewed, showed that lack of spontaneity in their sex lives affected participants' self-

esteem and perceptions of their masculinity. Experiences of penile shortening after surgery and inability to consummate intimate relationships through penetrative sex were also reported by the men as traumatic and affected marital communications with partners. Some participants reported feelings of guilt and inadequacy in meeting their partners' sexual needs and expressed fear at the possibility that their wives may look elsewhere for sexual pleasure. In contrast, other participants noted that openly discussing their concerns with their wives helped them to devise alternative means of maintaining intimacy without the act of penetrative sex. This was reported to help men in the latter group to retain their masculine respect through spousal caring, mutual understanding and intimacy. A qualitative approach used for the study enabled some insights into how participants' experiences of sexual dysfunction impacted on their marital relationships and perception of their sexuality following CaP treatment. However, the very small sample size (four participants), convenience sampling, lack of data saturation and details on how data was analysed or triangulated threatens the trustworthiness of the study. Moreover, the author did not provide the ethnic details of study participants which could help to assess the potential transferability of the study findings to BA and BC men with similar disease experience.

Evidence on the psychosocial impact of sexual dysfunction on Black men is limited. Rivers *et al* (2011) conducted qualitative interviews with twelve AA married couples purposively recruited through hospital records and a charity organisation, to explore their psychosocial concerns related to sexual functioning after CaP treatment. Erectile dysfunction was reported by 91.6 % (n=11) of the couples in which all the men were treated with either surgery or radiotherapy. Some couples (n=5) also reported reduced libido after CaP treatment. Findings showed that men and their partners had conflicting views regarding their experiences of sexual dysfunction. The men were primarily concerned about the impact of sexual dysfunction

on their quality of life, and this subsequently impacted on their perceptions of masculinity and personal self-esteem. Partners on the other hand (all of whom were female) were less bothered about declined sexual function and activity but more bothered about the men's survival and wellness. Limited information on how to deal with their sexual challenges, lack of professional psychosexual support for couples and minimal spousal communications contributed towards the psychosocial distress experienced by most couples in the study. This study provided useful evidence into the psychosocial impact of sexual dysfunction among AA men and their partners. However, lack of data which explored other aspects of the CaP experience (for example, urine incontinence and fatigue) highlighted a gap in the holistic understanding of such other issues related to psychosocial functioning among Black men and their partners. Exclusion of men above the age of 70 years and those with unmarried partners from the study also suggest that the experiences of such Black men may require further exploration. This was also a US-based study which has a different socio-cultural context to the UK.

2.3.2.2 *Urine incontinence*

Many men have also reported varying degrees of urinary incontinence following CaP treatment in which those who undergo radical prostatectomy often report worse incontinence outcomes compared with those who had other treatment procedures such as radiotherapy or brachytherapy (van Tol-Geerdink *et al.* 2013). This has been attributed to possible damage to surrounding nerves whilst removing the prostate gland during radical prostatectomy. Ranging from symptoms of frequent urination, urine leakage and loose bladder, urinary incontinence has been shown to have severe implications on men's self-esteem, independence, work and social lives post-treatment (Roth *et al.* 2008; Darwish-Yassine *et al.* 2014).

Qualitative findings from Grunfeld *et al's* (2013) study identified that some of their participants reported feelings of embarrassment, disruptions in their usual routines and negative perceptions of their masculine identity due to the impact of urinary incontinence on their ability and desire to return to work post-treatment for CaP. The study, which involved fifty CaP survivors consisting of White (n=38), Black (n=9) and Asian/Chinese (n=6) men who were in paid employment before their CaP diagnosis, identified clear links between urinary incontinence and men's daily work and social lives. The majority of participants in this study were in white collar jobs and the authors suggested an in-depth investigation of men in blue collar jobs as the latter often report greater difficulties in returning to work post-treatment for CaP (Grunfeld *et al.* 2013). The lower representation of Black participants in the study and lack of specific data on their ethnic affiliation within the Black racial group also suggest that the impact of urine incontinence on the working lives of BA/BC men treated for CaP and how this may impact on the personal and cultural perceptions of their masculinity may require further exploration.

2.3.2.3 *Fatigue*

Further psychosocial impact of CaP has been attributed to treatment-related fatigue (American Cancer Society [ACS] 2018). Many men have reportedly experienced varying degrees of fatigue following treatment for CaP, depending on the treatment option (Larkin *et al.* 2014). Fatigue in this context has been defined as a chronic subjective feeling of exhaustion experienced after treatment for CaP which often restricts men's usual daily activities (ACS 2018). Fatigue affects between 55% to 100% of patients with CaP at various stages of their CaP post-treatment journey in which those treated with radiation therapy and hormone therapy often report more severe cases of fatigue (Hickok *et al.* 2005; Ukoli *et al.* 2006, Gavin *et al.* 2015)

compared with men treated with surgery. Findings from a longitudinal case control study conducted by Alt *et al* (2011) showed an association between radiation therapy and cancer-related fatigue as their participants with CaP (n=14) reported more experiences of fatigue after treatment than the control group (n=12) who did not undergo radiation therapy. Fatigue may result from possible anaemia, build-up of harmful waste products and formation of pro-inflammatory cytokines^g which may follow radiotherapy (ACS 2018). Reduced testosterone levels and decline in voluntary muscle function due to reduced bone mass could further lead to fatigue in patients treated with hormone replacement therapy (Pirl *et al.* 2008). Likewise, the effects of anaesthesia, intensive use of pain killers/sedatives, irregular sleep patterns, pre and post-operative food deprivation, confinement and worry have been known to cause fatigue in patients treated with prostatectomy (Larkin *et al.* 2014).

Fatigue has been shown to negatively impact on men's social lives (such as sexual relationship, sporting activities) and affect their physical, mental, emotional and social well-being after treatment for CaP (Ukoli *et al.* 2006; ACS 2018). Given the cultural expectations for BA/BC men to be the main breadwinner for their nuclear and extended families (Kolawole *et al.* 2012), there are indications that limitations imposed by fatigue on their work lives may have even greater psychosocial implications for these men. Studies which have explored this phenomenon among BA/BC men are currently lacking within the CaP literature.

2.3.2.4 *Current support to help men deal with treatment side effects*

Depending on the existence of co-morbidities and patient age/choice, there are medical and non-medical measures available to assist CaP patients deal with physical symptoms of treatment side effects. For example, drugs like Viagra, Cialis and Levitra, penile injections and

suppositories, vacuum therapy and prosthetic penis are medical inventions available to treat erectile issues (Pahlajani *et al.* 2012; Fode *et al.* 2013). Similarly, clinical pelvic floor exercises done twice to thrice daily, taking less caffeine and avoiding constipation have been suggested to improve symptoms of urinary incontinence (MacDonald *et al.* 2007, NICE 2014). Getting adequate rest, engaging in moderate daily physical activity/exercise and ensuring a good diet have been recommended to help manage post-treatment fatigue in patients with CaP (Cramp and Byron-Daniel 2012). Nonetheless, providing effective psychosocial support which can be integrated with available medical and non-medical interventions could produce a more balanced approach towards improving the physical, mental and social well-being of CaP survivors and their partners (Larkin *et al.* 2014). Again, this is currently underexplored in the literature especially among the high risk BA and BC populations.

2.4 Explaining key concepts

To improve understanding of the context of this study, it is essential to define and clarify some key background concepts. These include race, ethnicity, culture, sexuality and sex.

2.4.1 Race, ethnicity and culture

Race and ethnicity have emerged as fundamental concepts in health which require clear definitions as they often bring up complex and controversial ethical issues (Bhopal 2004; Antai 2011; Odimegwu and Somefun 2017). These concepts have continued to generate debate among various disciplines including anthropologists, social psychologists and sociologists with regards to their definitions and conceptual meanings and no consensus has so far been reached regarding where and how best to use these terms when studying ethnic minority populations (Bhopal 2004;

Jaspal and Cinnirella 2012). The inconsistent use of race and ethnicity interchangeably by many researchers further highlights the existence of complex conceptual and practical difficulties in differentiating between the two concepts (Afshari and Bhopal 2002; Bhopal 2006; Ford and Harawa 2010). As global efforts are steered towards reducing health inequalities and promoting improved healthcare access and health outcomes among different populations, it has become important to understand how race and ethnicity specifically impact on people's health experiences and outcomes (Ford and Kelly 2005; Bhopal 2006; Antai 2011; Odimegwu and Somefun 2017). Each of the concepts: race, ethnicity and culture; are now discussed in detail.

The emergence of the concept 'race' dates back to 1949 when it was first introduced into scientific literature by Buffon and has since been associated more with biological/physical features and ancestral origin than cultural characteristics (Senior and Bhopal 1994; Agyemang *et al.* 2005). The biological definition of race has evolved over time since the end of the Second World War. Modern definitions now embody social constructions rather than biological features only (Afshari and Bhopal 2002). However, evidence indicates that biological features (such as skin colour, genetic make-up) and ancestral origin remain fundamental qualities on which social definitions of race are founded (Bhopal 2004).

Bhopal (2004) notes that the term 'ethnicity' (derived from the Greek word 'ethno' meaning 'nation') depicts a multidimensional feature which identifies a group of people based on unique cultural characteristics. These include language and traditions which emanate from shared geographical and genealogical origins (Bhopal 2004). Dein (2004) added that ethnicity also encapsulates cultural and religious beliefs, mutual ancestral origins and perception of self. These multidimensional characteristics make ethnicity rather difficult to measure as it can be regarded a fluid concept which is often socially-constructed or self-ascribed and stands the risk of

constantly changing with time (Bhopal 2004). This view was supported by Ford and Harawa (2010) although they further noted that ethnicity should be viewed from both attributional and relational perspectives. Attributional (or intrinsic) relates to peculiar sociocultural characteristics which define a group of people (for example, country of birth and ancestral origin). Relational (or extrinsic) attributes describe the association between certain ethnically-defined populations and the society where they are located (for example, nationality, migration status, religion and language) (Ford and Harawa 2010). Jaspal and Cinnirella (2012) argue that these attributional and relational factors are not fixed and may be subjectively interpreted based on a researcher's epistemological stance. Considering the arguments highlighted above and the continuing debate in this area, it can be suggested that collating demographic data on both attributional and relational qualities could facilitate a substantial understanding of ethnicity when investigating specific health phenomena among ethnic minority populations such as BAs and BCs.

In seeking to identify and categorise people based on ethnicity, existing evidence highlights that self-ascription is increasingly gaining popularity although this is subjective and may change over time and circumstances (Agyemang *et al.* 2005). Having noted the fluidity of the concept 'ethnicity' whereby it can incorporate both traditional features (such as ancestry, place of birth, genetic make-up) and social constructs (such as culture, self-ascription, migration history, nationality), it is preferred over 'race' in categorising this study's population and in discussing their health experiences and specific needs following treatment for CaP (Bhopal 2004; Ford and Harawa 2010; Jaspal and Cinnirella 2012).

Research which has explored ethnic disparities in the post-treatment experiences of men treated for CaP is currently sparse, especially among BA and BC groups. Rivas *et al.* (2016) conducted a qualitative metasynthesis of thirteen studies to investigate the experiences of US and

UK-based men with CaP and their partners. Findings indicated ethnicity influenced participants' experiences and coping with CaP across the individual studies reviewed. For example, compared with Caucasian men and other members of the BME group (for example, Hispanic), Black men (AA) reported a magnified impact of sexual dysfunction on their masculine identity and this substantially contributed to their reluctant attitude towards public disclosure of their CaP. Using spirituality and religion as coping mechanisms were also more commonly reported among the Black men than Caucasians. The review provided useful insight into ethnic disparities in experiences and coping with CaP, but as none of the studies in the review included BA/BC participants, there is need for more in-depth exploration of this phenomenon among this population.

Culture is an important aspect of ethnicity and it has remained a key determinant of health and health behaviour (Kagawa-Singer *et al.* 2010). Culture involves genealogically-shared beliefs, values and practices which influence how people perceive and respond to health messages and healthcare services (Karbani *et al.* 2011). Kagawa-Singer *et al.* (2010) notes an underestimation of the contribution of culture to health inequalities and suggests the potential effect of providing culturally sensitive cancer care to advance better outcomes among ethnic minority populations is yet to be fully explored. Livingston *et al.* (2013) further notes the importance of acknowledging the presence of diversity in the cultural characteristics and behaviour of members within the Black racial group irrespective of their shared genetic make-up and skin colour. For example, evidence shows that although BAs/BCs and AAs are from the same racial origin due to their shared attributional factors (for example, 'Black' ancestry, skin colour and genetic affiliations) (Ben-Shlomo *et al.* 2008), their differing relational contexts contributes to cultural differences in the customs and traditions which shape their lifestyles,

belief systems, health behaviours and healthcare experiences (Oppenheimer 2001, Agyemang *et al.* 2005; Livingston *et al.* 2013). Unfortunately, the observed inconsistencies in the gathering and reporting of ethnic data have further made it difficult to identify explicit cultural diversities and seem to pose a challenge in providing targeted and culturally-appropriate cancer care for different members within the broader Black group (for example, BAs and BCs).

Very few studies have examined culture within the context of CaP in Black men. Machirori *et al.* (2018) recently conducted a scoping review to investigate the relationship between culture and Black men's beliefs towards CaP. Findings from a thematic analysis of the 25 studies included in the review showed that cultural taboos around CaP discussions were aggravated by negativities associated with cancer especially when it affects the prostate. Seeking help for health issues was also identified as not consistent with Black men's ideas of being an ideal man and this further influenced the attitude of participants in the main studies towards CaP. Cultural and gender barriers in patient-healthcare communications on a perceived private subject were also reported as hampering Black men's access and utilisation of healthcare services for CaP issues. Underpinning the conduct of the scoping review with a methodological framework (Arksey and O'Malley 2005) and addressing an under-researched subject highlight the strength of the study. However, there was lack of clarity in the reporting style which made it difficult to identify the nuanced cultural differences among the different members of the Black racial group included in the individual studies. Moreover, lack of specific details on the individual studies included made it difficult to assess either the generalisability or transferability of the review findings to UK-based BA and BC men, taking into account acculturation factors. In particular, absence of partner data and lack of clear distinction between studies which involved 'healthy' Black men and those who had already been diagnosed and treated for CaP limits the relevance of

this review to understanding the psychosocial experiences and support needs of BA/BC men with CaP and their partners.

Considering the rich ethnic diversity of immigrants and indigenous populations in the UK, there has been considerable effort by policy makers to reduce inequalities in cancer outcomes and improve access to affordable healthcare services (NHS England 2016). However, like their other ethnic minority counterparts, evidence suggests that BAs and BCs still record much lower uptake of cancer programmes (for example, breast and cervical screening programmes, PSA screening), thus predisposing them to poorer cancer experiences due to delayed diagnosis (Thomas *et al.* 2005; Pedersen *et al.* 2012; DeSantis *et al.* 2014).

It is pertinent to focus attention on how an intersection between culture and ethnicity may interact with other determinants of health (such as age, gender, socio-economic status) to determine the cancer experiences and needs of BA/BC men with CaP and their partners. Such insights could help promote a holistic approach towards improving health outcomes among these high risk groups along the CaP journey (Viruell-Fentes *et al.* 2012). In a multicultural society (advanced by increasing migration) like the UK, Gregg and Saha (2006) assert that inevitable interactions between different ethnic communities may expose their members to possible changes to their indigenous cultural stance. This view was supported by Dein (2004) who noted that pure culture does not exist as the boundaries between different cultural groups are sometimes ambiguous. However, Brown (2014) argues that in spite of inter-ethnic interactions, culturally-informed ethnic boundaries continue to exist and play a pivotal role in observed inequalities in health experiences and outcomes as people still uphold a substantial degree of their indigenous cultural beliefs and attitudes and these often influence their health behaviours and experiences. This has been shown to be more evident among first and possibly second

generation immigrants who may be less influenced by the culture and social system of their host country (Taitt 2015). It has been argued that third and subsequent generations may find it easier to adopt the cultural beliefs and system of the host country (being their country of birth) as they may not have had a first-hand experience or direct exposure to their ancestral cultural beliefs and practices (Taitt 2015). For immigrant BA/BC populations, the role of culture in shaping their experiences of CaP and their access and utilisation of post-treatment support in the UK is not well understood.

2.4.2 Sexuality and sex: untangling complexities in definitions and meanings

Aggleton *et al* (2015) highlights that people's perceptions of their sexual experiences may be subjective as influenced by the social constructions of sex and sexuality within their cultural context. The inextricable link between sexuality and gender in which men's sexuality has been closely linked to their masculine identity has also been recognised in the literature (Benedict *et al.* 2014). This suggest an increasing need to investigate men's perceptions of sex and sexuality from a holistic point of view in order to better understand how experiences of sexual dysfunction may impact on them post-treatment for CaP. Understanding these concepts could also help to appreciate the psychosocial impact of treatment-related sexual dysfunction on a couple's intimate relationship after treatment for CaP.

Defining the concept of sexuality is often difficult as it is arguably a relative term whose definition is usually shaped by a given historical and socio-cultural context (Aggleton *et al.* 2015). In light of the confusing ambiguity between sex and sexuality, different authors over the years have sought to differentiate between the two terms. Lamb and Woods (1981) opined that sexuality results from a complex interaction between biological, family tree, cultural and social

factors and this makes it a difficult concept for individuals, researchers and health professionals to agree on. Girts (1990) succinctly described sex as an act and sexuality as the personality. Elaborating on this, Rice (2000) described sexuality as a much broader term which incorporates biological make-up (gender sex), personal identity and inter-personal relationship with others while sex connotes sexual activity. Supporting this view, other authors (for example, Stausmire 2004; Redelman 2008) explained that sexuality is an enduring part of human identity lasting from birth till death and is not restricted by age, physical make-up, health status or functional ability.

The World Health Organisation (WHO) in collaboration with the Pan American Health Organisation (PAHO) and the World Association for Sexology (WAS) highlight the importance of having general agreed definitions for sex and sexuality (PAHO, WHO 2000). This is necessary to facilitate effective communication, information distribution and development of essential interventions for improved sexual health (PAHO, WHO 2000). In light of this, Greenberg *et al.* (2013) defined sexuality as an embodiment of sex, gender, sexual orientation/identity, emotional bond and reproduction as influenced by an interplay between biological, cultural, socio-economic, psychosocial and religious factors. In other words, sexuality extends beyond physical sex to other wider social constructs, including the individual's relationship context. Both sexuality and sex form fundamental aspects of sexual health which the WHO (2017) defines as a state of physical, mental and social wellbeing in which individuals are capable of having pleasurable, mutually-acceptable and satisfying intimate experiences and relationships. This infers that sexual experiences are influenced both by physical sex and a more socially-constructed sexuality. Hence, the negative impact of physical aspects of sexual dysfunction on the psychosocial well-being of men and their partners after CaP treatment, should

not be undermined. Within the BA/BC cultural context, the importance of sex to men's sexuality and masculine identity is well documented in the literature (Coormasingh 2012; Bamidele *et al.* 2017a). Associating idealistic masculine identity with sexual performances involving multiple partners and earlier in life (Phillips 2005; Geressu 2016) and an ability to reproduce children (Plummer 2013; Case and Gordon 2016) further suggests that BA and BC men may be more psychologically distressed by sexual dysfunction after CaP treatment.

2.5 Some relevant theories: highlighting strengths and gaps

Different types of theories exist in the health research literature and are broadly classified as either formal or substantive theories depending on their purposes and philosophical perspectives from which they are viewed (Glaser and Strauss 2017). Formal theories are often underpinned by objectivism and aimed at generalisations (Sutphin *et al.* 2013) whilst substantive theories are usually underpinned by interpretivism and explain a particular idea within a given context (Glaser and Strauss 2017). In other words, formal theories are about wider applications, whilst substantive theories are specific to a particular context. Within the CaP research area and in particular for this current study, a theory is needed to improve current limited understanding of how BA/BC men and their partners navigate the CaP experience, their support mechanism and specific needs within their own socio-cultural context. Given the mass of existing theories which could potentially be considered to help understand these phenomena, it was imperative to limit discussion to the ones perceived to be most relevant as informed by the following key considerations.

Firstly, it was essential to consider the physical side effects of CaP treatment which fundamentally underpin the psychosocial experiences of affected men and their partners. For

example, evidence shows that treatment-related sexual dysfunction touches the core of men's masculinity, their sexuality and relationship with their partners (McCaughan *et al.* 2015). The gender-specificity (male cancer) of the CaP illness coupled with the contextual interpretation and enactment of masculine roles and identities may also influence the experiences of men with CaP and their partners. For these reasons, relevant masculinity theories (Courtenay 2000; 2009) were considered.

Secondly, the ethnic minority nature of the study population was considered. There are postulations that ethnicity and culture intersect with a myriad of other factors (for example, gender, age, socio-economic factors) to influence their health experiences and behaviours, especially towards cancer (Mulugeta 2014). Hence within the health behaviour theories, the Health Belief Model (HBM) (Strecher and Rosenstock 1997) was considered as this has been widely used in health research involving ethnic minority groups. The theory 'cancer through Black eyes' was also considered because of its specific focus on the views of BA/BC men regarding cancer (Mulugeta *et al.* 2017).

Thirdly, the high survival rates and chronic nature of CaP imply that men and partners are bound to live with long term treatment side effects which may necessitate them to devise diverse coping strategies and support mechanisms along the disease journey (Zhou *et al.* 2010). This provided the rationale to also consider some coping theories which also incorporate social support (e.g. Lazarus and Folkman 1984). Each of these theories are now discussed.

2.5.1 Masculinity theories

Over the years, different theories have emerged on gender and health in which the concept of masculinity has been shown to greatly impact on men's health experiences and

determine their health outcomes (Connell 2005; Courtenay 2009; Wall and Kristjanson 2005).

Whilst ‘sex’ has been used to denote the biological and reproductive features which differentiates a man from a woman, the term ‘gender’ has been more broadly used to encapsulate the social and culturally constructed roles and behaviours which are attributed to each of these identities (that is, masculinity or femininity) (Courtenay 2000; Phillips 2005; Ostlin *et al.* 2006).

Amidst this, there are social and cultural stereotypes around masculinity in which the prominent theory of hegemonic masculinity (which has a patriarchal undertone) plays an important role in placing socially-constructed expectations on men to be non-emotional, tenacious, inexpressive and self-sufficient even when faced with debilitating issues such treatment side effects of CaP (Courtenay 2000; Campbell *et al.* 2012). Hegemonic masculinity also views women as the subordinate, dependent parties who are expected to be more submissive and less in control of their emotions, making them more responsive to seeking help than men (Hess *et al.* 2009; Ocho and Green 2013). It is clear that such gender stereotypes have become deeply embedded in cultural beliefs and values resulting in a complicated intersection which undeniably predicates how men respond and cope with diseases (Wall and Kristjanson 2005; Gannon *et al.* 2010). More importantly, research has shown that masculine gender stereotypes which are often inculcated from childhood and developed through adulthood have substantial consequences on men’s health behaviours and outcomes within the African-Caribbean communities (Burns and Mahalik 2007; Seymour-Smith *et al.* 2016).

Whereas allegedly less traditional masculinity theories such as complicit and marginalised masculinity have evolved to challenge the tenets of hegemonic masculinity (Connell 2005), these theories also exhibit social constructionist undertones regarding how men should handle their physical and emotional concerns when faced with distressing issues (Connell

2005). Arguments around the complicit masculinity theory reveal idealistic expectations from the society for men to still uphold the hegemonic idea in the face of a constantly changing society even if it is just in a passive rather than practical way (Demetriou 2001; Connell 2005). Connell (2005) later argued that the practical activities of most men nowadays do not reflect the ‘culturally ideal’ hegemonic practice. In reality, men’s traditional perception and attitude towards their masculine identity may be modified following debilitating illness experiences such as CaP.

In relation to CaP, socially-constructed masculinity scripts often influence how men experience and cope with the disease in which upholding traditional hegemonic beliefs of masculinity have been reported to worsen men’s adjustment to treatment side effects (Helgeson and Lepore 2004; Burns and Mahalik 2006; Campbell *et al.* 2012). Campbell *et al.* (2012) used questionnaires to examine the role of masculinity beliefs in predicting psychosocial functioning among 59 AA treated for CaP who were recruited through community outreach and referrals by clinicians. Findings showed that after controlling for age, existence of co-morbidities and income, strong associations existed between participants’ adherence to traditional masculinity views and their psychosocial outcomes after CaP treatment. For example, participants who conformed to traditional masculinity expectations to be self-reliant and dominant reported higher levels of anxiety and depression ($P < .01$) and reduced functional well-being ($P < .01$). The men viewed depending on others as diminishing their masculinity. Although the study provided important overview into how masculinity beliefs determined the psychosocial health of AA men with CaP, its small sample size of 59 participants and homogeneous population of AA men limits its generalisability to other men from other cultures within the Black racial group who live in a different demographic setting apart from the US. More importantly, there is need for more in-

depth investigation through qualitative studies, into how men's upholding of traditional masculinity views may also impact on the psychosocial experiences of their partners, especially among understudied BA and BC populations.

2.5.2 The Health Belief Model

Over the years, a variety of social cognition theories have been successfully used to predict and explain people's behaviour in relation to their health and social environment. One of such theories is the HBM which was considered in this study because of its wide use in health research involving ethnic minority groups (Pasick 2008; Champion and Skinner 2008). HBM has emerged as a prominent psychological model widely used to explain and forecast people's preventative health behaviours at individual levels (Conner and Norman 2005; Thomas *et al.* 2005).

Historically HBM was developed to predict and explain people's health behaviours attitudes and beliefs in relation to their taking up of health messages and participating in health prevention programmes (Pasick 2008). The HBM has later been used to analyse how people respond to disease symptoms, diagnosis and treatment (Spector *et al.* 2009; Carter *et al.* 2009). Developed by Rosenstock and colleagues in the early 1950s after a failed free tuberculosis screening program, the HBM theorises that initiating health behavioural change by an individual is not only influenced by mere knowledge and skill (Strecher and Rosenstock 1997). An individual's perceived susceptibility to a particular disease (risk perception), the perceived severity of such disease, perceived barriers and perceived benefits of taking recommended actions to reduce the risk, often determine their decision to take such actions (for example attending cancer screening programmes) (Strecher and Rosenstock 1997; Hayden 2009). The

HBM has been amended over time to suggest that individuals also need to believe in their capacity to initiate and maintain health-related actions (self-efficacy) when triggered by cues to action (such as disease symptoms, educational information) in order to overcome their perceived barriers to undertaking recommended behavioural changes (Conner and Norman 2005; Hayden 2009).

Although the HBM has gained wide prominence and has been successfully applied in health promotion research, it is not without limitations which critics have identified as its individualistic focus and lack of explicit consideration for cultural factors (Poss 2001, Taitt 2015). There is growing evidence to conclude that an individual's risk perception of disease (especially among BME groups) is often underpinned by cultural beliefs (for example, witchcraft and type of diet) (Champion and Skinner 2008; Kagawa-Singer *et al.* 2010; Karbani *et al.* 2011; Bamidele *et al.* 2017b). Among Black men, cultural beliefs that CaP is a White man's illness (Atulomah *et al.* 2010), associated with old age (Nakandi *et al.* 2013; Owens *et al.* 2015), can be controlled through diet (Friedman *et al.* 2009), and can be avoided by not being promiscuous (Olapade-Olaopa *et al.* 2014); have all been shown to influence their risk perception of CaP and consequently their help-seeking behaviour towards diagnosis and treatment.

Whilst the HBM may be relevant to provide some insights into the help-seeking behaviour of BA and BC men in relation to health promotion for early diagnosis, it may not address their pattern of behaviour when it comes to their access and utilisation of post-treatment support care. The predominant focus of the HBM on primary and secondary prevention strategies also suggests that it may be more applicable to BA and BC men in this study if the aim was on improving their uptake of CaP screening and getting promptly treated if diagnosed. The broadness of the HBM also does not allow for a contextual understanding of how to address the

support needs of BA and BC groups through intervention development after CaP treatment. Therefore, there is need for a substantive context-specific theory to explore these phenomena.

2.5.3 Cancer through Black eyes

A previous study (Mulugeta *et al.* 2017) developed a substantive theory of ‘cancer through Black eyes’ to understand the knowledge and attitude of BA/BC men towards cancer. The theory sought to explain the perceptions of 27 UK-based BA/BC men recruited in England regarding cancer. The theory suggests that risk perceptions, lifestyle, mistrust in healthcare services, and limited knowledge of cancer, were barriers to early cancer diagnosis among BA/BC men. In addition to these, lack of national prostate screening programmes and associating diagnostic procedures such as the DRE with homosexuality (which is a taboo and stigmatised subject within the BA/BC cultural setting) were also identified as specifically influencing the health behaviours of BA/BC men towards CaP.

The theory ‘cancer through Black eyes’ articulated the views of BA/BC men towards cancer in general without a specific focus on CaP nor the implications of post-treatment side effects for men and partners within this cultural setting. The theory reiterates the construct of the HBM regarding the influence of an individual’s risk perception on his/her attitude and behaviour towards cancer and cancer services. ‘Cancer through Black eyes’ provides contextual insights which could be used in health promotion activities to engage with BA/BC population in order to improve their seeking help for early cancer diagnosis. However, the theory was developed from the views of healthy BA/BC men who had not experienced CaP treatment (or treatment for any type of cancer) diagnosis and did not include partners’ data. This limits the usefulness of ‘cancer

through Black eyes' to inform the development of post-treatment psychosocial support for BA/BC men treated for CaP and their partners.

2.5.4 Coping theories

Coping has been defined as the cognitive and behavioural efforts aimed at managing a situation evaluated as beyond the control of an individual's personal and environmental resources (Folkman *et al.* 1986). Over the years, different authors (e.g. Lazarus and Folkman 1984; McCrae and Consta 1986; Folkman *et al.* 1986; Pierce *et al.* 1996) have developed theories to explain the mechanisms involved in individual's coping with 'stressful' situations in which the seminal work by Lazarus and Folkman (1984) has remained prominent. According to Lazarus and Folkman (1986), coping can either be directed at dealing with the stressor (something which cause distresses such as CaP treatment side effects) or controlling the emotions instigated by the presence of the stressor. Constructs from the Lazarus and Folkman's (1984) coping theory further highlight the cognitive (thought process) and behavioural (corresponding action) aspects of coping may be fluid depending on an individual's context and specific circumstances at a particular time. Within this, it is believed that an individual's interpretation of reality is shaped by their perception of the graveness of the situation which in turn influences their coping strategies and behaviours (Lazarus and Folkman 1984; Gonzalez *et al.* 1990). Other coping theories (McCrae and Consta 1986; Pierce *et al.* 1996; Folkman *et al.* 1986) have also identified individual (internal) and situational (external) factors as further influencing the coping behaviour and strategies of individuals regardless of being faced with a similar experience or challenge. Relating this to the CaP experience, the physical experience of

having CaP coupled with the patient's socio-cultural context have been shown to intersect and determine how they respond and cope with the disease (Bamidele *et al.* 2017a).

Folkman *et al.* (1986) also articulated that an individual's appraisal of the severity of their illness is often subjective and influences how they respond and cope with such illness. In light of this, they (Folkman *et al.* 1986) identified eight coping strategies which include taking responsibility, problem-solving, accessing social support, positivity, distancing, avoiding escape, self-control and confronting. These strategies may be classified as either positive or negative coping depending on an individual's personal and situational contexts. In a later work, Folkman and Nathan (2011) further identified religion and spirituality as coping strategies which resonate with Rosenstiel and Keefe's (1983) report that prayer helped their participants with lower back pain to deal with their chronic illness.

Studies which have explored the mechanisms of coping among Black men with CaP are currently scarce as the few studies which have explored this phenomenon among CaP patients have mostly involved Caucasian participants (Mehnert *et al.* 2010; Paterson *et al.* 2016). Evidence from these studies highlights a diversity in the cognitive and behavioural patterns among men in dealing with CaP which underscores the subjectivity in an individual's coping experiences. For example, accessing social support as a coping strategy to improve psychosocial outcomes along the CaP journey is well recognised in the literature (Roberts *et al.* 2006; Zhou *et al.* 2010; Harandi *et al.* 2017). However, findings from a UK-based study by Paterson *et al.* (2016) which examined the link between social support and coping as influential on the psychological outcomes of men with CaP showed that this may not always be the case. The study which recruited 12 men as case studies from a larger longitudinal study showed that social support was reported as a positive coping strategy by only three men (n=3), whilst the majority

of the other participants found it less useful to cope with their psychological issues (n=6). Two men reported a negative effect of social support as a coping strategy. Whilst this study provided an important insight into an underexplored phenomenon, its small size limits its generalisability. Further qualitative research could also help elaborate on these findings and identify what type of support would be most ideal to help men cope better with the challenges of CaP within their particular context. This could particularly be useful among BA/BC men with CaP and their partners as their coping mechanisms and support preferences are currently underexplored.




Having reviewed the broader literature as discussed from the beginning of this chapter, a more focused literature review was systematically conducted to examine in-depth studies that have specifically explored the post-treatment experiences of BA/BC men treated for CaP. Findings from the studies were synthesised to identify specific areas requiring further exploration.

2.6 Life after prostate cancer: a systematic literature review and thematic synthesis of the post-treatment experiences of Black African and Black Caribbean men [Paper 1]

The review examined the post-treatment experiences of BA and BC men treated for CaP. The methodological framework for systematic literature review by Thomas and Harden (2008) guided the conduct of the review. Search for eligible studies was conducted across seven databases. Four qualitative studies which met the review's inclusion criteria were identified and critically appraised. Sample size ranged from two to seventeen participants mostly aged over 65 years old. Thematic synthesis of identified studies yielded four broad themes: symptom experience; healthcare experience; marital and social relationships; and coping. Findings highlighted that participants were distressed by experiences of sexual dysfunction and urinary

incontinence post-treatment for CaP. Men's distress was further compounded by lack of information on what to expect post-treatment and how to deal with it; limited involvement in treatment decision-making; cultural stereotyping from HCPs; fatalistic views regarding cancer; and fear of partner abandonment due to unsatisfactory sexual relationships. Resilience and religion/spirituality were the men's predominant coping strategies. Partners were not included in any of the studies.

Life after prostate cancer: A systematic literature review and thematic synthesis of the post-treatment experiences of Black African and Black Caribbean men

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Evidence shows that there are significant ethnic variations in prostate cancer prevalence and outcomes. Specifically, Black African and Black Caribbean men may encounter different post-treatment experiences than Caucasian men due to their disproportionately higher risk of being diagnosed with advanced prostate cancer. But to date, no review of these experiences has been undertaken. This review synthesised findings from existing literature on the post-treatment experiences of Black African and Black Caribbean men with prostate cancer and identified pertinent issues which may be useful to inform practice and future research. Seven databases were systematically searched using developed search terms. Four qualitative studies were identified and critically appraised. Findings are summarised under four main themes: symptom experience, healthcare experience, marital and social relationships and coping strategies. Cultural definitions of masculinity influenced the meanings men gave to their post-treatment experiences. While men's experiences of healthcare varied, the provision of professional support to address their post-treatment distress was lacking. Men derived most support from wives, peers and church communities. A culturally sensitive approach which recognises diversity among Black African and Black Caribbean populations and treats individuals within their religious and socio-cultural contexts could potentially improve men's post-treatment experiences. Areas for further research were also identified.

KEYWORDS

Black African, Black Caribbean, experience, men, post-treatment, prostate cancer

1 | INTRODUCTION

In addition to reducing the prevalence of cancer, the National Health Service (NHS) England's cancer strategy also aims to speed up cancer diagnosis leading to better treatments, improved health-care and long-term quality of life for cancer survivors (NHS England, 2016). For prostate cancer, evidence shows that there are significant ethnic variations in its prevalence and outcomes (Marmot et al., 2010; Prostate Cancer UK (PCUK), 2014a). Specifically, Black African (BA) and Black Caribbean (BC) men have two to three times higher risk of being diagnosed with advanced prostate cancer than Caucasian men (Ben-Shlomo et al., 2008; Bray, Ren, Masuyer, & Ferlay, 2013; Rebbeck et al., 2013; Williams, 2014). Although older men are more at risk of prostate cancer, among BA and BC men, the risk is also increasing for younger men (Ben-Shlomo et al., 2008; PCUK, 2014b).

A number of reasons for ethnic variations in prostate cancer prevalence and outcomes have been presented in the literature. These include: genetic-environmental interactions (Ben-Shlomo et al., 2008; Chornokur, Dalton, Borysova, & Kumar, 2011; Odedina et al., 2011; Rebbeck et al., 2013), knowledge of cancer and cancer symptoms (Pedersen, Armes, & Ream, 2012; Rajbabu et al., 2007), cultural barriers including the role of masculinity (being the breadwinner, being 'tough', demonstrating sexual prowess and virility), fatalistic beliefs, superstitious beliefs, loss of sexuality, and stigma (Mulugeta, 2014; Pedersen et al., 2012). Available evidence also highlights, that Black and Minority Ethnic (BME) groups report poor experiences of healthcare due to a lack of cultural sensitivity in healthcare delivery (Das-Munshi, Leavey, Stansfeld, & Prince, 2012; Pinder, Ferguson, & Moller, 2016). As a consequence, a combination of factors contributes to delays in seeking help for prostate cancer (Pedersen et al., 2012), resulting in late diagnosis, poorer post-treatment outcomes and higher mortality rates among BA and BC populations (Jones & Chinegwundoh, 2014; Rebbeck et al., 2013).

With improved access to early diagnosis and treatment, survival rates from prostate cancer have increased and many men now live up to at least five to 10 years post-diagnosis in the absence of co-morbidities (Cancer Research UK, 2014). As a result of these advances in treatment and improved survival rates, men who survive prostate cancer are living longer with post-treatment complications such as sexual/erectile problems, incontinence issues, pain, 'menopause-like' feelings and fatigue (Gavin et al., 2015). Such treatment side effects have been shown to affect men's ability to perform their daily activities and roles including: work (Grunfeld, Drudge-Coates, Rixon, Eaton, & Cooper, 2013; Roth, Weinberger, & Nelson, 2008), marital role as the breadwinner and sexual partner (Coomarsingh, 2012; Gerressu, 2016; Phillips, 2005), therefore impacting on their psychosocial wellbeing and quality of life (Gavin et al., 2015; McCaughan, McKenna, McSorley, & Parahoo, 2015; McCaughan et al., 2013).

The National Institute of Health and Care Excellence (NICE) recommend the provision of appropriate support care to help men deal

with the side effects of prostate cancer treatment (NICE, 2015). To deliver such post-treatment support care, there is need for cultural sensitivity, taking into account the cultural interpretation of prostate cancer among BA and BC populations, and how this may influence their experiences and coping with the disease. There is however, a dearth of evidence showing the post-treatment experiences of BA and BC men and how they cope with prostate cancer, including its impact on their masculinity. Previous reviews have reported the experiences of a Caucasian sample (e.g. King et al., 2015) or BME group as a whole (Rivas et al., 2016), but have not specifically explored the role of ethnicity in the post-treatment experiences of BA and BC men with prostate cancer. Those that have had a BA and BC focus, have looked at knowledge and perceptions of prostate screening (Pedersen et al., 2012) or their support needs (Cremin, 2015). Hence, this review aims to address this knowledge gap by synthesising findings from existing literature on the post-treatment experiences of BA and BC men with prostate cancer, and identify pertinent issues that need to be addressed to ensure improved satisfaction with care, better post-treatment experiences and improved quality of care for this target group. In addition, the review aims to explore areas for future research.

2 | METHODS

As recommended by Aveyard (2014), a systematic approach was adopted in identifying relevant studies to address the review aim.

2.1 | Search strategy

Existing literature was systematically searched to identify articles relating to the post-treatment experiences of prostate cancer among BA and BC men. The search was conducted between November 2015 and June 2016 across seven bibliographic databases namely: CINAHL plus, Medline Ovid, Psych Info, Cochrane Central, Embase, ProQuest and Scopus. Search terms were developed using the following key words: prostate, cancer, prostatic neoplasm, experience, coping, outcome, treatment outcome, post-treatment, Black African, Black Caribbean, African, Caribbean, African-Caribbean, Afro-Caribbean, Black. Truncation (*) and quotation mark (") were used where appropriate to capture all variants of keywords whilst Boolean operators 'OR' and 'AND' were also used to broaden and limit search results as appropriate.

Choice of database to search and development of search terms were made in consultation with an experienced subject librarian. An author search was conducted on Scopus to identify similar and related articles from authors in the research area and journal alerts were set up for research updates. The grey literature was also searched for unpublished empirical research (dissertations, conference proceedings, research reports). Finally, the reference lists of selected papers were hand-searched whilst main authors were also contacted via email for possible updates to their papers and their knowledge of any other relevant studies.

2.2 | Inclusion and exclusion criteria

A set of inclusion and exclusion criteria (Table 1) were set to ensure a focused, credible and significant review within a feasible time frame (Centre for Reviews and Dissemination 2009). Initial searches showed that there was a dearth of research evidence relating to post-treatment experiences of BA and BC men with prostate cancer. Therefore, the authors considered it reasonable not to exclude articles based on publication date or study setting. Hence, empirical studies which addressed the post-treatment experiences of prostate cancer among BA and BC men, and published in English were included in the review. Studies including different types of cancers were included if they had separate data on prostate cancer. Publications which involved both Black and Caucasian participants, but did not report their respective views separately, were excluded. Studies related to African American men were also excluded because they are the indigenous Blacks in America and their socio-cultural experiences may be different from that of immigrant BA and BC men (Agyemang, Bhopal, & Bruijnzeels, 2005; Odedina et al., 2011).

2.3 | Screening

A Prisma diagram of the study illustrating the process used to select articles relevant to be included in the review is presented in Appendix A. The initial search yielded 932 publications from which 702 duplicates were removed. The title and abstracts of the remaining 230 publications were then read and a further 93 were considered irrelevant and removed. The remaining 137 papers were assessed for inclusion by two authors (OB and EM). Two other authors (BML and HM) provided a second opinion where needed. Four research studies were considered eligible for this review. None of the four publications were identified from grey literature.

2.4 | Data extraction and critical appraisal

Data were managed using an extraction sheet created on Microsoft Excel (2016). The four selected papers were further reviewed by five authors (OB, EM, HM, BML and KP) and differences in opinion around data extraction and appraisal were resolved via discussion. The methodological quality and trustworthiness of selected studies

were appraised using the Critical Appraisal Skills Programme (CASP, 2013) tool for qualitative research (Appendix B).

2.5 | Identification and synthesis of themes

All four selected studies were qualitative, therefore, we carried out a thematic synthesis based on the approach recommended by Thomas and Harden (2008). Descriptive themes were developed by mapping participants' views and experiences in each of the papers in relation to the review aim. Discussions among members of the research team (OB, EM, HM and KP) facilitated a mutual agreement on the descriptive themes which emerged across the papers reviewed. This was then followed by comparison and interpretation of findings across the different studies to generate new analytical constructs (Thomas & Harden, 2008).

3 | RESULTS

3.1 | Overview of papers

The four qualitative studies were published between 2005 and 2013 (Anderson, Marshall-Lucette, & Webb, 2013; Bache, Bhui, Dein, & Korszun, 2012; Gray, Fergus, & Fitch, 2005; Nanton & Dale, 2011). All four studies had used individual interviews to explore the post-treatment experiences of BA and BC men with prostate cancer, in relation to their respective study aims. Table 2 presents, in a chronological order, detailed characteristics of the four selected studies. Each of the selected studies had undergone peer-review prior to being published in their respective journals. A critical appraisal of each study demonstrated good methodological quality (Appendix B). Therefore, all four studies were included in this review. With regards to their usefulness, the studies by Gray et al. (2005) and Nanton and Dale (2011) provided more in-depth and richer data to meet the aim of this review compared with the studies by Bache et al. (2012) and Anderson et al. (2013). Nevertheless, the latter two studies were also included as they had BA participants in their studies and the limited evidence they presented was still considered useful to provide a glimpse into the experiences after prostate cancer for this grossly under-researched population.

Three out of the four studies were conducted in the UK (Anderson et al., 2013; Bache et al., 2012; Nanton & Dale, 2011) whilst the fourth study was conducted in Canada (Gray et al., 2005). The demographic and clinical details of the participants in the studies were not fully and consistently reported. Hence, what emerged was a patchy profile with missing data. A total of 27 participants (22 BC, 4 BA men and 1 unknown) aged between 50–83 years old were interviewed across the four studies. Many participants were married ($n = 12$, marital status of others were not stated) and in blue collar jobs (manual/wage-earning [$n = 13$]). The treatment received by most participants included: active surveillance ($n = 2$), radical prostatectomy ($n = 12$), radiotherapy ($n = 2$), radiotherapy with hormone therapy ($n = 5$), prostatectomy with radiotherapy and hormone therapy ($n = 1$). The length of time since treatment ranged from ongoing treatment to 15 years post-diagnosis. Demographics of

TABLE 1 Inclusion and exclusion criteria

Inclusion criteria	Exclusion criteria
Studies which provided empirical data on the post-treatment experiences of BA and BC men with prostate cancer	Studies on the post-treatment experiences of men with prostate cancer where the views of BA and BC participants were not reported separately
Published in English language	Studies involving African American men
	Studies which focused on prostate screening
	Epidemiological and intervention studies
	Anecdotal evidence

TABLE 2 Summary of reviewed studies

Author(s)/year of publication	Study aim	Methodological approach	Sampling	Sample characteristics	Treatment received	How long since post-treatment	Study limitations
Gray et al. (2005) (Canada)	To reveal how prostate cancer affects the lives of individual Black men and to show how a narrative approach can contribute to health psychology	Narrative approach using interviews	Community-based snowball and purposive sampling	2 (1BC, 1Black Canadian); 62–70 years; blue collar job; married	Surgery	One year post-treatment	Only one BC participant and study setting being Canada suggest limitation in universal applicability of their findings published over 11 years ago; no details regarding ethical considerations or approval; post-treatment support needs of BA/BC were not explored. Both participants were well educated and well aware of prostate cancer before taking part in the study
Nanton & Dale (2011) (UK)	To investigate the role of ethnicity in determining the prostate cancer experiences of first generation African-Caribbean men and their perception of healthcare service received	Thematic analysis using interviews	Community-based snowball sampling	16 (15BC, 1NA); 50–83 years; mostly blue collar jobs; 11 married and 5 widowed.	Surgery; hormone therapy; radiotherapy + hormone, catheter only, prostatectomy + radiotherapy + hormones	Average 2 years since diagnosis	Only Jamaicans in the sample, hence no representative of other Caribbean countries; men's post-treatment experience in relation to their work lives was not explored in-depth; men's suggestions on ways of improving their support care were not explored
Bache et al. 2012 (UK)	To investigate coping behaviours, care experiences and help-seeking behaviours of African and Black Caribbean cancer survivors	Framework analysis using interviews	Purposive sampling	8 (5 women and 3 men (1BA, 2BC); 70–90 years; job type and marital status not stated	Radiotherapy	Average 15 years since diagnosis	Lack of in-depth exploration of BA/BC men's post-treatment experiences; small sample size (3 men); older men sampled; most of the study findings reflect experiences/perceptions of female cancer survivors; men's post-treatment support care needs were not identified; insufficient demographic details; all participants recruited from an existing support group; hence they were already seeking help and support. The findings will not necessarily apply to those who do not normally seek help. Very scant findings from the three men with prostate cancer were reported in this mixed cancer study
Anderson et al. 2013 (UK)	To explore African and Afro-Caribbean men's experiences of prostate cancer and their understanding of its associated risks	Phenomenology Using interviews	Purposive sampling	7 men (3BA, 4BC); 60–76 years old; blue and white collar jobs; marital status not stated	Active surveillance, radical prostatectomy, hormone therapy + radiotherapy, hormone therapy alone	On-going treatment (up to 3 years post diagnosis)	Limited overview of BA/BC men's post-treatment experiences of prostate cancer; men's post-treatment support care needs were not identified

the sample for each of the four studies is presented in Table 2. Thirteen descriptive themes emerged across the reviewed papers and were categorised into four broader themes namely: symptom experience, healthcare experience, marital and social relationships and coping strategies.

3.2 | Symptom experience

Whilst variations existed in the type and severity of treatment side effects experienced, sexual dysfunction following treatment emerged as a generally shared post-treatment complication which affected men across all the studies. Although some men also reported distressing experience of urine incontinence (Nanton & Dale, 2011), others reported that they were spared from incontinence issues after their prostate cancer treatment (Gray et al., 2005).

3.2.1 | Dealing with treatment side effects

A recurring and prominent theme across three of the four studies related to sexual problems following prostate cancer and how these participants perceived masculinity and their marital relationships (Anderson et al., 2013; Gray et al., 2005; Nanton & Dale, 2011). Findings from the review showed that sexual potency was a significant determinant of men's personal feelings of their masculine identity and this in turn influenced their help-seeking for prostate cancer (Anderson et al., 2013; Gray et al., 2005; Nanton & Dale, 2011). Men were as concerned over partial and uncertain erections (Gray et al., 2005) as they were about complete sexual dysfunction post-treatment (Anderson et al., 2013; Nanton & Dale, 2011):

'there are things that come into your mind now that prevent you from enjoying sex' (Gray et al., 2005; participant quote)

However, some men expressed the fear of losing their wives due to their inability to provide sexual satisfaction following their illness:

'Also when the chemo [therapy] was really having its effect on me, I was really afraid that she [wife] would leave me' (Anderson et al., 2013; participant quote)

In dealing with their sexual problems, some men were prescribed medications by their doctors (Nanton & Dale, 2011) whilst others reported struggle in dealing with such sexual difficulties (Gray et al., 2005). In spite of their advanced years in age and co-morbid conditions with diabetes which appeared to have compounded reduced sexual functioning in some participants, men expressed deep feelings of disappointment at their sexual loss post-treatment. As one recollected from a conversation with a doctor:

'you can't do that as when you were young age man, but me tell him I can accept that but it shouldn't have all gone' (Nanton & Dale, 2011; participant quote)

Daily management of post-treatment incontinence was also a major concern to most participants in Nanton and Dale's (2011) study as this had caused significant restrictions on many aspects of their lives. Beyond physical limitations to men's daily lives, incontinence problems affected men psychosocially with some reporting feelings of stress, embarrassment and inconvenience, due to delayed and limited supply of incontinence aids by healthcare professionals.

3.3 | Healthcare experience

Disparities were observed across the four studies in men's individual perceptions of their healthcare experiences. Some men reported more positive experiences (Bache et al., 2012; Gray et al., 2005) than others (Nanton & Dale, 2011). BA and BC men's perceptions of their healthcare experience were reflected across four subthemes namely: decision-making for treatment choice, treatment side effects, experience of healthcare services and communication with healthcare professionals.

3.3.1 | Decision-making

Men's involvement in the decision-making process for their treatment choice and managing post-treatment side effects varied across and within the studies reviewed. Some men were more engaged than others in the decision-making process with their healthcare professionals (Bache et al., 2012; Gray et al., 2005; Nanton & Dale, 2011) whereas others relied solely on their doctor's prescription, and seldom asked questions regarding treatment choice or how to manage side effects (Bache et al., 2012; Nanton & Dale, 2011). Increased knowledge and awareness through personal research and consultation with known peer survivors also contributed to some men's engagement with their doctors to decide treatment options (Gray et al., 2005; Nanton & Dale, 2011). Other men admitted little prostate cancer awareness prior to their diagnosis (Nanton & Dale, 2011). Although generally men expressed confidence in their doctor's competence, some felt pressure to comply with certain prescribed treatments as these were viewed to be a natural course of the prostate cancer trajectory:

'It was something like compulsory that they...you have to have it because I first started to rebel against this injection. The doctor even said to me, he said 'forget how many hundred pounds it costs for one of these injections' and 'I am fortunate to be given the type of treatment.' (Nanton & Dale, 2011; participant quote)

'I'd have said they are the boss, you know they said radiotherapy, check it out, could be best for you. I just get on with it. I don't force.' (Bache et al., 2012; participant quote)

3.3.2 | Experience of healthcare service

Diverse reactions in men's perceptions of the healthcare service were identified from the review. Positive reports of the healthcare service were mostly associated with: successful treatment outcomes facilitated by doctors' technical skills (Gray et al., 2005), doctors' communication skills (Bache et al., 2012), availability of radical treatment procedures (Nanton & Dale, 2011) and the presence of a Black nurse post-surgery, which was perceived as an indication of culturally sensitive caring (Gray et al., 2005). Although there were no reports of obvious racial discrimination in any of the studies, some participants felt that some healthcare professionals resorted to stereotyping and described Black men as being *"secretive and reluctant to seek treatment"* (Gray et al., 2005). Men's concerns regarding side effects of hormone therapy were also perceived by some healthcare professionals as a masculinity issue (Nanton & Dale, 2011):

'And I explained to the doctor...I said, 'I don't want to have this injection' because it's a thing that bloats you up see and I don't want to do that ...it gives you breasts and I said 'No' and he's telling me about being like macho man and I said 'No, I do not want to be a macho man, I just want to be me.' (Nanton & Dale, 2011; participant quote)

Several participants expressed negative experiences of the healthcare service which they attributed to hasty and unsympathetic attitude devoid of respect for personal dignity from some healthcare professionals. Such negative experiences were further compounded by lack of adequate information and support to deal with post-treatment side effects especially with regards to incontinence (Nanton & Dale, 2011). Most men did not report being offered any psychosocial support post-treatment but the few who were signposted to support agencies complained of complex referral procedures and inadequate services which resulted in feelings of disappointment with such services (Nanton & Dale, 2011):

'(I went to see) the welfare rights and she was explaining to me that I could get help for certain things, but... like, 'why don't you try the Macmillan...?' but by the time you're phoning here and phoning there, I said 'I can't worry about it' (Nanton & Dale, 2011; participant quote)

3.3.3 | Communication with healthcare professionals

With the exception of men in the study by Bache et al. (2012) who reported receiving full information prior to treatment, this review established from the other three studies (Anderson et al., 2013; Gray et al., 2005; Nanton & Dale, 2011) that there was limited communication between men and healthcare professionals especially in relation to post-treatment side effects or how to deal with such. This further impacted on the men's perception of their healthcare experience.

However, men's perceptions of such limited conversations differed across the reviewed studies. Some men reported that their doctor's candid prescription of surgery without mentioning potential side effects boosted their confidence and enhanced their coping with the disease (Gray et al., 2005). Others noted that their doctors were not sensitive when communicating their prostate cancer diagnosis and that the little information they received made them less prepared for the treatment side effects they experienced (Nanton & Dale, 2011). When men had reservations about certain aspects of their care, some did not communicate their uncertainties to a healthcare professional. Men also noted cultural barriers in discussing sexual matters with healthcare professionals:

'my opinion is this: I think most African and Caribbean men find it a taboo to talk about anything apart from normal illness, anything about sex life, they think it's a bit taboo to discuss it with their doctors or GPs, especially if they have a female GP.' (Anderson et al., 2013; participant quote)

In spite of the varied reactions to existing limited doctor-patient communication, men generally expressed a desire for more information through rapport-building between doctor and patient to help them (patients) cope with prostate cancer and its treatment side effects (Gray et al., 2005; Nanton & Dale, 2011):

'You're not going to sit there and tell me about my prostate and that's all we talk about. No, we talk about other things too.' (Gray et al., 2005; participant quote)

3.4 | Marital and social relationships

Sexual difficulties after prostate cancer treatment and the potential impact on their intimate marital relationships were reported by men in all the four studies. They also admitted communication barriers in discussing such sexual concerns with their wives. Incontinence issues were also seen to restrict men's daily personal and social lives.

3.4.1 | Discussing sexual concerns with wives

Although many participants in most of the studies reviewed (Anderson et al., 2013; Gray et al., 2005; Nanton & Dale, 2011) experienced sexual problems after their prostate cancer treatment, there was no indication of communication between couples regarding such sexual issues. A participant in one of the studies admitted that difficulty in discussing sexual concerns with his wife was due to *'lack of camaraderie'* existent in the Caribbean culture (Gray et al., 2005). The same participant also stressed that discussing sexual issues with wives and initiating sex could pose an additional burden for men at this stage of their prostate cancer journey. Men noted that their inability to meet with cultural expectations to be a leader in their marriage(s) could potentially lead to dysfunction in their marital relationships post-treatment for prostate cancer.

There were suggestions that health professionals could serve as intermediaries in facilitating marital communication by engaging wives in active discussions on their new roles to initiate sexual activity as a way of helping to deal with their husband's sexual difficulties after prostate cancer treatment. One participant went further in advocating how this could be achieved:

'he should have called her into the office and said, these are your new responsibilities, stick to them and it would help, and these are the reasons why it would help, and be beneficial in the end.' (Gray *et al.*, 2005; participant quote).

3.4.2 | Work life

Whilst the impact of prostate cancer treatment on men's working lives was not explored in most of the reviewed studies, one participant's narratives in Gray *et al.* (2005) showed a positive experience as his prostate cancer advanced his 'prominence' both within and outside his workplace. Such prominence was reflected in this participant's increased request to be involved in the development of novel health promotion activities at his workplace, which further contributed to his perception of positive post-treatment experience.

3.5 | Coping strategies

There were variations across these four studies regarding how men coped with their prostate cancer. Different internal and external factors enhanced better coping in some men than others.

3.5.1 | Resilience

Participants in the four studies (Anderson *et al.*, 2013; Bache *et al.*, 2012; Gray *et al.*, 2005; Nanton & Dale, 2011), generally showed a resilient attitude towards their prostate cancer. Such resilience was more observed among the younger men as many of them were reported to have received their diagnosis calmly (Nanton & Dale, 2011) in spite of their fatalistic beliefs about prostate cancer and initial anxiety over potential loss of sexual function (Anderson *et al.*, 2013; Nanton & Dale, 2011). In some cases, men's resilience was motivated by their desire to carry on with life (Bache *et al.*, 2012) and continue living a happy family life post-prostate cancer (Anderson *et al.*, 2013). Some men noted that their personal will-power enhanced their successful surgery and coping post-surgery (Gray *et al.*, 2005). Others who perceived going through the diagnostic and treatment processes as imperative, maintained this resilient attitude along their post-treatment journey (Anderson *et al.*, 2013) and resolved to manage their prostate cancer on a day-to-day basis (Nanton & Dale, 2011):

'there is certain amount of reluctance or whatever it is... to have to go, but my own personal situation; I felt that if something was wrong, painful and ugly as it all might

have been, that had to go through with it' (Anderson *et al.*, 2013; participant quote)

'so it has given me extra resolve not to brood about the fact that I have prostate cancer.' (Bache *et al.*, 2012; participant quote)

3.5.2 | Religious faith

A key finding across the studies was the adaptation of religious faith as a coping strategy. Many men described a personal conviction in the ability of God to help them cope with their prostate cancer (Bache *et al.*, 2012; Nanton & Dale, 2011). Some men reported that prayers from others also contributed to their successful surgery (Gray *et al.*, 2005). They described how their religious beliefs not only empowered them to think positively about their diagnosis, but also gave them the strength to accept and manage resulting post-treatment issues (Bache *et al.*, 2012):

'Oh it has strengthened my mind because it has given me the necessary will power to accept what has come to me and also to accept the consequences, Yes' (Bache *et al.*, 2012; participant quote)

'you see as I always call on the Lord and all of these things I said 'Lord Jesus help me to go through this thing' and then I go through it and I came home' (Nanton & Dale, 2011; participant quote)

3.5.3 | Traditional remedies

Although not a recurring theme across other studies, most men in Nanton and Dale's (2011) study portrayed a staunch belief in the use of traditional remedies and have continued to use them to complement their medical treatment for their prostate cancer. Even though this was predominant among the older participants in the study, younger men who were less familiar with such traditional remedies also used dietary supplements in addition to their medical treatment:

'...they say pumpkin seeds are good for you, so I started to buy some' (Nanton & Dale, 2011; participant quote)

3.5.4 | Social support

The review showed that BA and BC men with prostate cancer had very limited sources of professional support. Most of their post-treatment support had been provided by their wives, immediate families, other peer survivors and the church. In some instances, and especially among those without access to such support, there were feelings of helplessness:

'I don't know who to go to for help here' (Nanton & Dale, 2011; participant quote)

Referral to support organisations was only mentioned in the Nanton & Dale's study (2011) and the few men involved expressed disappointment at the services received which they described as unsuitable to meet their post-treatment needs. Even where study participants were recruited through a support group (Bache et al., 2012), their support experience and perceptions of services provided by such organisation were not explored.

3.5.5 | Wife and other family support

The majority of married men described their wives as very supportive along their prostate cancer journey (Gray et al., 2005; Nanton & Dale, 2011). Men in Anderson et al.'s (2013) study also expressed fear of being abandoned by their wives because of how prostate cancer complications affected their sexual abilities but most participants in the three other studies (Anderson et al., 2013; Gray et al., 2005; Nanton & Dale, 2011) did not report such concerns. Wives steered the men to seek help for their cancer symptoms and also provided them with support to live with prostate cancer (Gray et al., 2005; Nanton & Dale, 2011).

'...She has been extremely supportive' (Gray et al., 2005; participant quote)

Older men and those without wives or family members nearby reported feeling isolated and having poorer coping abilities than those with wives. Men who were carers for their wives and/or for a family member with an illness or disability also reported less able to cope with their prostate cancer than those with no caring responsibilities (Nanton & Dale, 2011).

3.5.6 | Peer support from and for others with prostate cancer

Findings identified that communicating with known peer survivors promoted greater confidence and greatly enhanced the ability of most BA and BC men to cope with their prostate cancer (Anderson et al., 2013; Gray et al., 2005; Nanton & Dale, 2011). However, there were variations across the studies in how men navigated such peer-support relationships. Whereas some men were direct beneficiaries of peer-support activities in seeking early diagnosis (Anderson et al., 2013), making treatment decisions (Gray et al., 2005; Nanton & Dale, 2011) and dealing with post-treatment issues (Nanton & Dale, 2011), others derived personal satisfaction from engaging in prostate cancer buddy activities which further enhanced their personal coping with their disease (Anderson et al., 2013; Gray et al., 2005):

'It's [prostate cancer] killing people in droves. Some have had the operation done, it's done poorly, and they are in pain. Some talk to me because they know I've

had it done. I'm willing to talk about it' (Anderson et al., 2013; participant quote)

In instances where their masculinity ideals were constructed around status and social relationship with peers, men noted that their disease experience further reinforced their prostate advocacy activities. This earned them increased recognitions and made them more 'famous' as peer supporters for other men with prostate cancer (Gray et al., 2005).

3.5.7 | Support from the church

Findings further showed that the church provided a highly valued source of support for BA and BC men with prostate cancer. Men acknowledged that the spiritual and moral support offered by the church were helpful on their disease journey:

'Well, apart from wife my church stands by me with my illness and my friends. Everybody who knew that you were ill will encourage you and that is the help I get. I didn't get it from any (other) organisations.' (Nanton & Dale, 2011; participant quote)

4 | DISCUSSION

This review aimed to synthesise findings from existing literature on the post-treatment experiences of BA and BC men with prostate cancer and identify pertinent issues that need to be addressed to ensure improved satisfaction with care, better post-treatment experiences and improved quality of care for this target group. The review also aimed to explore areas for future research. Findings from the review show that the experiences of BA and BC men with prostate cancer are similar to that of their Caucasian counterparts (King et al., 2015). There are however some indications within the findings of the four identified studies that there can be complex interactions between culture, age, gender and socio-economic factors. There are indications that culture may play an important part in shaping the experiences of BA and BC men post-treatment for prostate cancer than has been previously reported. We now discuss the findings from the four papers under three main themes: sexual dysfunction as a cultural threat to masculine identity, perception and use of healthcare services, and coping and social support.

4.1 | Sexual dysfunction as a cultural threat to masculine identity

The threat prostate cancer presents to masculine identities is well documented for Caucasian men (Appleton et al., 2015; Beck, Robinson, & Carlson, 2009; McCaughan et al., 2015; Roth et al., 2008). Evidence highlights that socio-cultural context plays an important role in the dominant constructions of what it is to be a man (or woman) (Peplau, Veniegas, Taylor, & DeBro, 1999). BA and BC masculine identities centre on their sexuality which is defined by virility and prowess (Case & Gordon, 2016). For example, the expectation that men will have

more than one sexual partner (Coomarsingh, 2012; Gerressu, 2016; Plummer, 2013) and engage in sexual activities at an earlier age than their Caucasian counterparts is well documented (Gerressu, 2016). For some of the participants in the studies reviewed, sexual dysfunction (physical and psychological) was a main concern impacting on them performing their masculine identities. The fear of being abandoned by their wives was also mentioned by some participants (Anderson et al., 2013) in this review. The self and social stigma associated with not being able to perform their masculine sexual roles has been noted as one of the causes of delays in seeking treatment for prostate cancer and post-treatment psychosocial stress among Black men (Kendrick, 2010; Mulugeta, 2014; Pedersen et al., 2012).

Sexual dysfunction in men can therefore 'upset' the balance in male–female relationships because it undermines dominant cultural ideas of BA and BC men's masculinity. In one of the studies in this review (Gray et al., 2005), a participant commented on the '*lack of camaraderie*' that he thinks is common in Caribbean marriages. He found it difficult to talk about sexual dysfunction with his wife and wished that the urologist had '*called her into the office*' and told her about '*her new responsibilities*' (p. 78). However, many Caribbean women have been noted to lack the power to determine when and how to have sex (Allen, 1997; Coomarsingh, 2012). If this is the case, relinquishing their customary leadership roles in initiating sexual activity may be hard for these men. Arguably, such cultural stereotypes and beliefs may have changed over time among these ethnic migrants due to acculturation to their host country (Taitt, 2015). Nevertheless, Brown (2014) argues that despite inter-ethnic acculturations, people still uphold a substantial degree of their indigenous cultural beliefs and attitudes which often influence their health behaviours and play a pivotal role in observed ethnic inequalities in health experiences and outcomes.

4.2 | Perception and use of healthcare services

Similar to their Caucasian counterparts (King et al., 2015), men in the reviewed studies reported positive and negative experiences with healthcare services. Technical skills of their doctors in carrying out successful treatment procedures, mostly accounted for the men's perceptions of positive healthcare experience (Gray et al., 2005). However, unmet information needs, communication barriers in discussing their sexual difficulties with healthcare professionals and perceptions of cultural stereotypes from healthcare professionals, contributed to negative experiences of healthcare reported by many participants (Anderson et al., 2013; Gray et al., 2005; Nanton & Dale, 2011). These further resonate with findings from previous studies (Papadopoulos & Lees, 2004; Viruell-Fuentes, Miranda, & Abdulrahim, 2012) in which language barrier and cultural stereotypes contributed to perceptions of poor healthcare experiences among ethnic minority populations.

BA and BC men's experiences of stereotyping from healthcare professionals and their (men's) perception of discussing sexual concerns as a 'taboo', highlight the need for cultural sensitivity in patient–healthcare professional communication in relation to prostate cancer. Pedersen et al. (2012) further reported that African-Caribbean men often showed a lack of trust in healthcare

professionals and the healthcare system, mainly due to inadequate communication with health professionals. A national survey of the experiences of patients with cancer in the UK showed that Black patients with cancer reported less positive experiences of communication and collaborative care from healthcare professionals, compared with their Caucasian counterparts (Quality Health 2013). However, there were no data relating specifically to prostate cancer in this survey. There is need, therefore, to understand why there is lack of trust in healthcare professionals (Pedersen et al., 2012) and the reasons for the low satisfaction the Black population has with healthcare services in the UK.

4.3 | Coping and social support

Related to findings from studies involving Caucasian populations (Beck et al., 2009; Wootten et al., 2014), this review also showed that most BA and BC men were stoical in the way they coped with their condition and that wives played vital roles in providing daily support and motivating their men to seek help with their prostate cancer (Gray et al., 2005; Nanton & Dale, 2011). Narratives of poorer post-treatment coping among men without wives (Nanton & Dale, 2011) echo findings from Kazer et al. (2011) in which participants without partners in their study identified feelings of loneliness and greater psychological distress than those with partners.

However, despite BA and BC men's reports of psychological distress associated with sexual dysfunction and urinary incontinence post-treatment (Anderson et al., 2013; Nanton & Dale, 2011), there appears to be a lack of desirable professional support to help the men deal with such distress. Previous reviews on psychosocial interventions for prostate cancer survivors (Chambers, Pinnock, Lepore, Hughes, & O'Connell, 2011; McCaughan et al., 2013; Northouse et al., 2007) also suggest that Black men are being marginalised in this area. Hagen, GrantKalischuk, and Sanders (2007) noted that men's experiences of prostate cancer treatment are largely influenced by how much professional support and information they receive along their disease journey. Even where some men had been signposted to support services, men described such services as inappropriate and unsuitable to meet their needs (Nanton & Dale, 2011). Yet, reasons for such assessment or men's suggestions on areas for improvements were not reported in the study.

Close family members and friends, in particular other peers with prostate cancer, formed part of the support network for men in this review. The church emerged as a major source of social support for the men, most of whom also mentioned religious faith as a coping strategy for their prostate cancer (Bache et al., 2012; Gray et al., 2005; Nanton & Dale, 2011). The emergence of religious faith as a coping strategy in this review emphasises the prominent role of religion in the health experiences of ethnic minority populations (Koenig, 2012). Among the many ethnic groups in the UK, Black people have the highest rate of regular church attendance than other BME populations (TEARFUND, 2007). This is further reflected in the increasing number of majority Black churches in the UK (Akhazemea, 2015). Black populations report consistently higher church attendance (48%) compared to their Caucasian counterparts (15%) in the UK (TEARFUND, 2007). Findings

from a recent systematic review on 'prostate cancer and supportive care' (King et al., 2015) also revealed that out of twenty studies (which included Caucasians and other ethnic groups), only two studies identified church support; both studies had involved BC (Nanton & Dale, 2011) and African American participants (Rivers et al., 2012) respectively. This is further evidence of the interaction between culture and religion among most BA and BC populations (Akhazemea, 2015; Baruth et al., 2013). The church supports BA and BC populations by providing an enabling social network of individuals who share similar cultural values (Akhazemea, 2015). Collaborating with church leaders could potentially promote the development of culturally appropriate, yet spiritually acceptable interventions that will address the individual needs of BA and BC men with prostate cancer (Baruth et al., 2013).

4.4 | Study limitations and directions for future research

This review provides useful evidence on the post-treatment experiences of BA and BC men, indicating the centrality of culture in these experiences and highlighting key implications for healthcare practice. However, review findings may not be generalisable to the wider BA and BC population in the UK due to a number of limitations. The review comprised of only four studies. Although we had used an extensive search strategy, with the expert guidance of an experienced librarian, and also set up journal alerts to enable us to keep up to date with new research during the review period, including only studies published in English Language may have resulted in potentially relevant studies being missed in this review. Most of the narratives in the four studies included in this review, reflected the views of BC men (most of whom originated from Jamaica). It is essential to further explore the views of a more heterogeneous sample of BA and other BC men in order to gain more insight into their unique needs and how these can be best addressed. Lack of details regarding ethnicity in many participants' quotes in the studies made it difficult to differentiate the views of their BA participants from those of the BC men. This further makes the task of separating the intricate characteristics of these similar but different ethnic populations, more complex.

Many participants in the reviewed studies appeared to be well educated and positively inclined towards research participation and therefore may not be representative of the less educated, hard to research and less inclined to seek help BAs and BCs. Future research should devise more robust recruitment strategies which also incorporate snowballing through peer contact and religious leaders to access these hard-to-reach populations and make their voices heard.

There are some indications that partners of men with prostate cancer often undergo similar, or sometimes greater psychosocial distress (such as anxiety and depression) than the men themselves (Nelson & Kenowitz, 2013). Evidence related to Caucasian and African American populations show differing patterns in what contributes to men and their partners' psychosocial distress after prostate cancer treatment. Whereas men express greater concern regarding their sexual potency, partners report being more adversely affected by their men's experiences of urinary incontinence (Couper et al., 2006) and fear of losing

their men to prostate cancer (Rivers et al., 2011). The focus of this review was men themselves and none of the four studies made reference to the post-treatment experiences of partners of BA and BC men with prostate cancer nor identified their specific support needs. Research into partners' experience and needs relating to their men's prostate cancer is sorely needed.

Post-treatment incontinence usually poses the most challenging aspect of most men's prostate cancer experience in relation to their ability to return to paid work (work forms a crucial part of men's masculine identity) (Grunfeld et al., 2013). However, the impact of prostate cancer on the work lives of BA and BC men was not explored in any of the studies in this review. Noting that socio-economic advancement is a major motivating factor for BA and BC men's migration from Africa and the Caribbean (Brown, 2014; Nanton & Dale, 2011), there is need for future studies to explore the impact of prostate cancer treatment on the working lives of these under-researched ethnic men.

5 | IMPLICATIONS FOR PRACTICE

Findings from this review suggest the need for healthcare professionals to consider cultural issues without resorting to stereotypes in healthcare delivery for BA and BC men with prostate cancer. Undeniably, culture is a complex yet important determinant of health which requires in-depth understanding in order to address the post-treatment needs of minority ethnic men with prostate cancer. There is need to be cognisant of each individual's disease experience and unique information/communication needs and ensure that potential post-treatment side effects and how to manage such are clearly communicated to men. Wives/partners should also be included in such discussions and the specific ways in which they can help or be helped along their husbands'/partners' prostate cancer journey should be identified and addressed.

Healthcare professionals' intervention in facilitating intimate conversations among couples could also potentially help relieve undesirable sex-related burden among BA and BC men with prostate cancer. A person-centred approach which recognises the diversity among BA and BC populations and treats individuals within their religious and socio-cultural contexts could potentially promote improved healthcare experiences among prostate cancer survivors within these high-risk populations.

6 | NEW CONTRIBUTION TO KNOWLEDGE

6.1 | What we already know

BA and BC men have a disproportionately higher risk of developing prostate cancer but they are currently under-represented in research related to men's experiences and coping after prostate cancer treatment.

6.2 | What we do not know

Very little is known on how culture shapes the meanings BA and BC men attribute to their prostate cancer and how this in turn influences

their experiences and coping with the disease. Stand-alone evidence from the few individual studies on BA and BC men with prostate cancer do not adequately address this research gap.

6.3 | What our review contributes to existing literature

This is the first (to the best of our knowledge) systematic literature review which solely focuses on the post-treatment experiences of BA and BC men in relation to their cultural context. Our review highlights the need for increased cultural awareness which is devoid of stereotyping, among health professionals caring for men with prostate cancer. This review further provides broader and more in-depth evidence on BA and BC men's post-treatment experiences than in any of the individual studies, amplifying the men's cultural interpretation of prostate cancer and how their experiences differed from those of Caucasian men. The review also identified the church as a potential resource to reach out to BA and BC men in order to develop culturally appropriate, yet spiritually acceptable interventions that could improve their experiences after prostate cancer treatment.

7 | CONCLUSIONS

This review has identified that the post-treatment experiences of BA and BC men treated for prostate cancer can be different from those of Caucasian men. Sexual dysfunction following treatment, posed a particular threat to participants' identity as males of Caribbean and African descent. This in turn, affected the men's relationships with their partners. There were also varying levels of satisfaction among the BA and BC men in the identified studies regarding health services. Most support for these men was from wives/partners and their church communities. Finally, a number of areas for future research have been suggested. In particular, the experience of partners should be explored.

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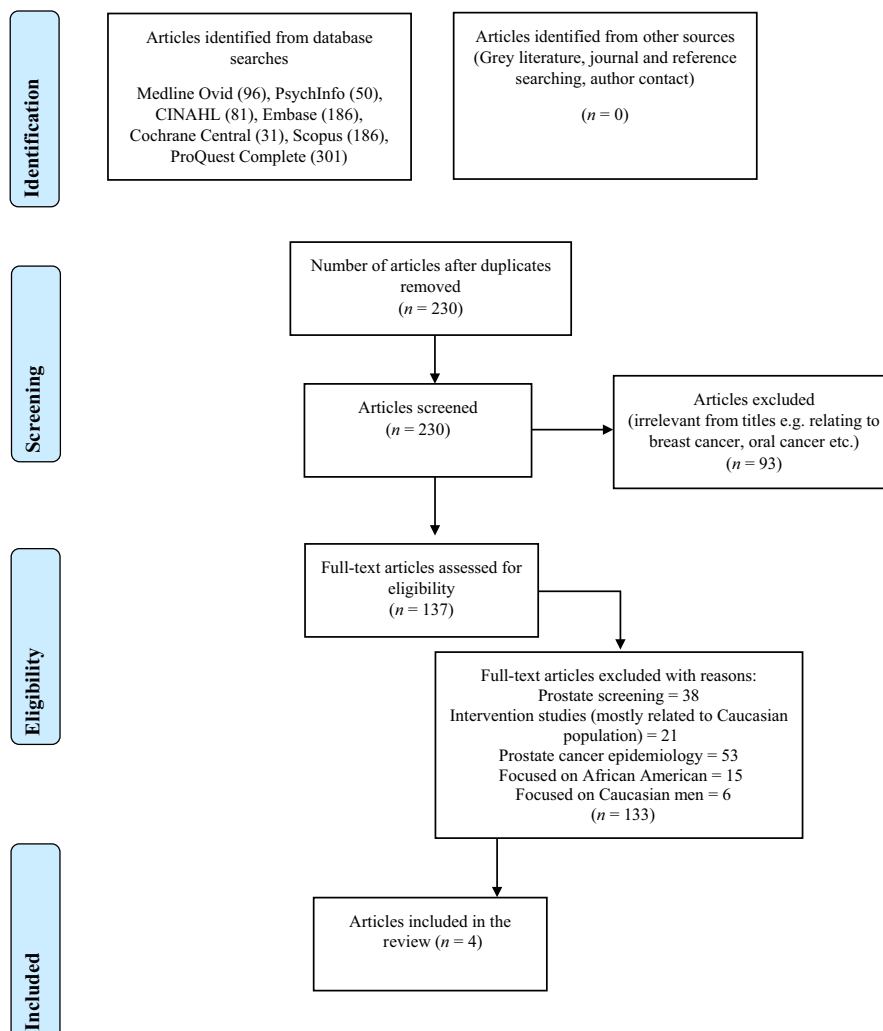
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APPENDIX A

Prisma flow chart of search strategy



APPENDIX B

Critical appraisal of selected studies using the CASP tool (2013)

Selected studies	Included clear statement of research aims?	Qualitative methodology appropriate?	Research design appropriate to address aims of the research?	Recruitment strategy appropriate to the aims of the research?	Data collected in a way that addressed research issue?	Relationship between researcher and participants adequately considered?	Ethical issues considered?	Data analysis sufficiently rigorous?	Included clear statement of findings?	How valuable is the research?
Gray et al. (2005)	Yes	Yes	Yes	Yes	Yes	Yes	Not clear	Yes	Yes	Provided in-depth insight into the post-treatment experience and concerns of individual BC men with prostate cancer
Nanton & Dale (2011)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Highlighted gaps in the literature, the implications for policy and practice and suggested areas for further research
Bache et al. (2012)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Had limited narratives from male participants, however pilot study identified coping strategies for African and Black Caribbean men with prostate cancer
Anderson et al. (2013)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Identified factors which determine BA and BC men's help-seeking for prostate cancer. Identified areas for further research

2.7 Research gaps identified in the literature

This chapter identified the need for further research due to the following gaps and limitations.

1. Very few studies have explored the psychosocial experiences of Black men and their partners after CaP treatment and the majority of these have focused on AA groups (Rivers *et al.* 2011; Rivers *et al.* 2012; Bowen 2015; Dickey and Ogunsanya 2018). Disparities in demographics and socio-cultural settings between the UK and US suggest that findings on AA groups may have limited applicability in informing psychosocial support for UK-based BA/BC groups.
2. Within the four reviewed studies which specifically focused on the post-treatment experiences of BA/BC men with CaP (**Paper 1**), the majority of the findings reflected the views of older Jamaican men. There was sparse evidence from younger men and those from other members of the BA/BC ethnic group. Evidence shows a higher prevalence of CaP among younger BA/BC men compared with Caucasians (PCUK 2016). High improvements in CaP survival rates imply that there may be a greater number of younger BA/BC men living with the side effects of CaP whose experiences and support needs have not been investigated. The patterns of behaviour of BA/BC men along the CaP journey was also not clearly articulated to help inform the development of culturally sensitive psychosocial support for them as this was not an objective in any of the individual studies reviewed.
3. Perhaps the most prominent gap in the evidence base for BA/BC groups was the lack of partner data in the studies reviewed in **Paper 1**. This indicates that partners' experiences and unique support needs within the BA/BC context are yet to be investigated. The observed high prevalence of gender inequality and acceptability of polygamy in some African cultures especially among BA men (Izugbara and Ezech 2010) suggests that their partners may have

unique post-treatment experiences of CaP. Moreover, immigrant partners of BA/BC CaP survivors may also experience certain barriers in expressing their support needs due to prevalent hegemonic masculinity stereotypes within the BA/BC culture (Eguavoen *et al.* 2007; Coomarsingh 2012).

4. Evidence suggests that people's health experiences are substantially influenced both by their attributional and relational contexts (Ford and Harawa 2010). An examination of the theories considered earlier in this chapter (Section 2.5) indicates they are mostly formal theories with rather broad perspectives. Whilst such theories may help to provide a clue into the dynamics of living with a CaP illness at a general level, the fluidity of individuals' specific illness experiences as shaped by their attributional and relational contexts highlights the limitations of these theories. There is need for a more substantive theory which could help to understand the patterns of behaviour (basic social processes) involved in the post-treatment experiences of BA/BC men with CaP and their partners within their specific context.

This PhD study sought to address the aforementioned gaps identified in the evidence base by setting the following aim and objectives:

2.8 Aim

The aim of the study was two-fold:

- a) To explore the psychosocial needs and how best to address them after prostate cancer treatment for Black African and Black Caribbean men and their partners;
- b) To develop a substantive theory that explains the experiences of Black African and Black Caribbean men with prostate cancer and their partners

2.8.1 Objectives

To achieve these aims the following objectives were set:

- i. To investigate the experiences of Black African and Black Caribbean men with prostate cancer and where applicable, also the experiences of their partners respectively;
- ii. To examine men's and partners' respective perceptions of support care after prostate cancer treatment;
- iii. To investigate from men's and partner's perspectives, what are their perceived individual needs and the needs of each other post-treatment for prostate cancer;
- iv. To investigate healthcare professionals' experiences and their perceptions of the needs of Black African and Black Caribbean men post-treatment for prostate cancer;
- v. To examine study participants' suggestions for interventions that could address the needs of Black African and Black Caribbean men with prostate cancer and their partners.

2.9 Summary

This chapter discussed key background literature, concepts and relevant theories reviewed prior to conducting this study. Review of the literature identified that socio-cultural context contributes to ethnic disparities in response and coping with the post-treatment challenges of CaP. Despite the disproportionately higher risk of CaP among BA/BC men, very few studies have explored their post-treatment experiences and psychosocial needs. Data on

partners' experiences and support needs within BA/BC group are even more scarce. The need for further research to address gaps in the evidence base was identified.

CHAPTER THREE: METHODOLOGY

3.1 Introduction

This chapter discusses how the research was conducted, highlighting the rationale for choosing constructivist ground theory. The chapter is presented in two sections. The first section presents the philosophical assumptions that informed the research design and approach used. The second section discusses the research design including sample, sampling, data collection, ethical considerations, data analysis, rigour and trustworthiness. A discussion on recruitment has been written up as a published paper (**Paper 2**) and is included at the end of section 3.3 in this chapter.

3.2 Philosophical assumptions: ontology, epistemology and methodology

Evidence highlights that the rigour and credibility of research findings could be strengthened by ensuring an alignment between the study's aims and objectives, the researcher's philosophical assumptions and the chosen research design (Richard and Morse 2007; Bryman 2015). Hence, it was considered pertinent to start this chapter by clarifying the philosophical assumptions which underpinned the development of the research design and consequently informed the approach used to address the study's aims and objectives (Section 2.8, Chapter Two). According to Creswell (2007), a researcher's choice of a particular research approach is broadly influenced by their ontological (definition of reality), epistemological (how reality is known) and methodological (research procedure) assumptions.

The researcher's ontological belief resonates with the relativist view that reality is multiple, subjective and often influenced by context and interpretation. The researcher's ontological views stemmed from her personal inclinations towards relativism, cultural affiliation with BA heritage, experience of living in a foreign country, interactions with people of diverse social status/cultural

backgrounds, narrative writing style and previous research experience with immigrant BA women in relation to breast screening uptake. Epistemologically, the researcher identified with interpretivism which postulates that reality should be discovered inductively (interpretivism) (Bryman 2015). Within interpretivism, social constructivism was chosen to underpin this study. This was informed by the researcher's realist ontological stance, combined with the fact that one of the research aims was to develop a substantive theory to enable in-depth understanding of an under-explored phenomenon. Social constructivism involves co-construction of knowledge with study participants as influenced both by their and the researcher's experiences and contexts (Birks and Mills 2015). The ontological and epistemological underpinnings of this study informed its methodology choice for constructivist grounded theory.

3.3 Research design

A qualitative design was considered most appropriate to guide the conduct of this study for the following reasons. Firstly, participants' perceptions of their psychosocial needs after CaP treatment may vary depending on their individual and social experiences following the diagnosis and treatment for the disease. Hence, using objective measurements such as surveys may not tease out from participants the in-depth knowledge and understanding required to effectively address such needs (Parahoo 2014). Secondly, this research was not aimed at testing existing theories (deduction) but to generate from participants' narratives a substantive theory (induction) which could provide a conceptual understanding of their poorly understood experiences after CaP treatment to inform intervention development (Creswell 2013). Thirdly, careful thought was given to the 'hard to reach' (difficult to access) (Sydor 2013) nature of BA and BC populations as evident in their underrepresentation in existing research and an anticipated difficulty in

recruiting a statistically significant sample size within the limited time available to conduct a quantitative or mixed methods research (Bryman 2015). Hence the need for a flexible but rigorous approach which could ensure access to a realistic number of participants within the limited time frame for conducting the research further informed the choice for a qualitative design. Some potentially applicable approaches within the qualitative paradigm were considered in which grounded theory was considered most suitable for this study.

3.3.1 Brief history on grounded theory

Grounded theory is a qualitative methodology which aims to inductively develop a theory through systematic data collection and analysis in order to understand pertinent issues affecting the study population from their own perspectives (Mills *et al.* 2006; Ramalho *et al.* 2015). Having its roots in sociology and dating back to 1967 when it was first developed by Glaser and Strauss (1967), grounded theory marked a significant turn in the recognition of the qualitative method as a credible and rigorous approach to research enquiry (Creswell 2007). Since then, grounded theory has further evolved and gained global prominence as an important qualitative methodology in health and social science research (Creswell 2007; Ghezeljeh and Emami 2009; Parahoo 2014). Other versions of grounded theory have also emerged and offer perspectives as to how this type of research should be conducted (Glaser 2007; Strauss and Corbin 2008; Charmaz 2014). Issues such as: philosophical perspectives; time and purpose of the literature review; process of data collection and analysis; and language use whilst coding data, have often been the focus of debates amongst renowned grounded theorists. However, they all agree on the exclusive and inductive ‘theory-development’ characteristic of this qualitative approach (Glaser and Strauss 1967; Charmaz 2014; Corbin and Strauss 2015; Ramalho *et al.* 2015).

3.3.2 Rationale for choosing constructivist grounded theory

Amidst the different versions of grounded theory, Charmaz's constructivist grounded theory (CGT) was preferred for this research. This was because CGT resonated with the social constructivist worldview of the researcher and would enable co-construction of knowledge between the researcher and study participants to better understand their experiences (Charmaz 2014). Using CGT approach also provided a flexible yet rigorous interpretive approach to developing a substantive context-specific theory which helped to delineate the varied basic social processes (patterns of behaviour) associated with the experiences and needs after CaP treatment for BA/BC men and their partners. This enhanced the potential of this study to make new contribution to knowledge through theory development (Foley and Timonen 2015). With the researcher methodologically situated at the centre of the research process (for example, coordinating data collection and analysis) (Mills *et al.* 2006), it was essential to acknowledge that her shared ethnicity and migration status (immigrant BA) with study participants and her earlier review of the literature, could potentially introduce bias in the knowledge construction process. To mitigate such potential research bias, she documented reflective (field notes and reflections on interviews) and theoretical (analytical interpretation of the data) memos and also discussed her interpretation of the data with her supervisors and study participants (theoretical sampling). Further details provided on theoretical sampling and the memos are provided in sections 3.3.4.2 and 3.4.3 respectively.

3.3.3 The sample

Driven by the research aims and theoretical sampling (see details in section 3.3.4.2), three different sample groups were involved in the study:

1. BA and BC men with CaP
2. Partners of BA or BC men with CaP
3. Healthcare professionals (HCPs)

Although HCPs were not part of the initial target sample, initial emerging themes from the men's interviews indicated a need to explore their (HCPs) views on the research phenomenon (see details at section on theoretical sampling 3.3.4.2). The inclusion and exclusion criteria for the study and their respective rationale are presented in Table 2.

Table 2: Inclusion and Exclusion Criteria for the Study

Sample Group	Inclusion Criteria	Exclusion Criteria
Men	BA or BC ethnic origin who had undergone treatment for CaP.	BA/BC men receiving palliative care. <i>Rationale:</i> Their needs were perceived as a different phenomenon which was beyond the scope of this study.
	Undergone treatment at least three months prior to participating in the study. <i>Rationale:</i> It was anticipated that from three months post-treatment onwards, many men would have recovered sufficiently to be able to participate in the study.	
	Aged 18 years and above. <i>Rationale:</i> Although CaP is unlikely to affect men as young as 18, evidence shows that BA/BC men may develop the disease earlier in life compared to men of other ethnic populations (PCUK 2016). In view of this, it was considered reasonable to apply the lowest applicable and legally acceptable age limit in order to ensure men were not excluded from the study on the basis of their age.	
	Resident in the UK. <i>Rationale:</i> This was a UK-based study.	
	Able to read, understand and speak English. <i>Rationale:</i> This was because of the intimate nature of the research topic, cost implications, and potential barriers to free, open and effective flow	

	<p>of communication if an interpreter was used. Hence, participants who could not read, speak or understand English were excluded.</p> <p>Men without partners were eligible to participate if they met the inclusion criteria as having a partner was not an eligibility criterion for their participation in the study.</p>	
Partners	<p>In an intimate or marital relationship with a BA or BC man who had undergone at least three months post active treatment for CaP. <i>Rationale:</i> Same as above for men.</p> <p>Resident in the UK. <i>Rationale:</i> Same as above for the men.</p> <p>Aged 18 years and above. <i>Rationale:</i> Eligible age to provide voluntary informed consent.</p> <p>Able to read, understand and speak English. <i>Rationale:</i> Same as above for the men.</p> <p>Could be of any ethnic origin. <i>Rationale:</i> Ethnicity only applied to the men to keep within the study context.</p> <p>Could be of any gender. <i>Rationale:</i> To ensure that no partner was excluded from participating in the study on account of their gender.</p> <p>Partners who met the inclusion criteria and were willing to participate were included regardless of whether their partner with CaP participated in the study or not.</p>	<p>Partners of BA/BC men with CaP receiving palliative care. <i>Rationale:</i> Same as above for the men.</p>
Healthcare Professionals	<p>HCPs working as part of an uro-oncology team (for example, oncologists, urologists, radiographers, clinical nurse specialists, uro-oncology nurses). <i>Rationale:</i> They are the key health professionals who provide care for men with CaP and would have had direct contact with these men at the most critical stages of their disease journey).</p> <p>Resident in the UK. <i>Rationale:</i> Same as for men and partners above.</p>	<p>Non-health professionals (For example, support workers). <i>Rationale:</i> They may not have direct contact with the men at the most critical stages of their disease journey) nor understand their needs after CaP treatment.</p>

3.3.4 Sampling and recruitment

The aim of this study was not to make statistical generalisations but to explore a poorly understood phenomenon in greater depth. Hence, nonprobability sampling procedures were used which included convenience, snowball⁸ and theoretical sampling as they aligned with the CGT method (Foley and Timonen 2015). Although theoretical sampling is the ideal sampling strategy in grounded theory research, it was pertinent to start off with convenience and snowball sampling in order to identify and access the participants needed to provide the preliminary data which then directed the subsequent interviews (Charmaz 2014).

3.3.4.1 Convenience and snowball sampling

Convenience and snowball sampling strategies were initially used to identify participants for this study before theoretical sampling was used. Recruiting participants for this research was particularly challenging due to their reputation as ‘hard to reach’ groups. Further thought was also given to the sparse population of BA/BC men with CaP in Northern Ireland. Initial exploration of recruitment in Northern Ireland showed it was unrealistic to recruit participants for this study in this part of the UK. The generally low population of BME groups in Northern Ireland (Northern Ireland Statistics and Research Agency [NISRA] 2018) may have further contributed to the difficulty in identifying BA/BC men with CaP. All the afore mentioned factors were duly considered early on in the research journey and discussed with supervisors. It was mutually decided to extend recruitment efforts to England which has a higher population of BA and BC groups (see discussion in Chapter One, section 1.3). Different possible strategies and avenues were then discussed and explored to maximise recruitment for the study. These included: contacting cancer charity organisations and churches; advertising the study on Black-focused radio stations

and their websites; networking with personal contacts and colleagues; collaborating with NHS hospital Trusts; and snowballing through men who had participated in the study. Eligible and willing participants were recruited in England (South England, East Central England and Greater London) between October 2016 and March 2018. A detailed discussion of the recruitment process, the barriers encountered and the factors which facilitated successful recruitment has been written up for publication (**Paper 2**) and is included at the end of this section. The effectiveness or non-effectiveness of the sampling strategies and avenues used have also been discussed in the **Paper 2**.

3.3.4.2 Theoretical sampling

Theoretical sampling involved following emerging themes from initial data and exploring them in greater depth in subsequent interviews until the developing theory was fully conceptualised and no further data was required (theoretical saturation^g) (Charmaz 2014; Foley and Timonen 2015). Whilst theoretical sampling guided what data was required to address gaps in emerging themes and facilitated exploration of variations within the data, it also informed where to get additional data to expand understanding of emerging findings. Emerging themes from the first set of interviews with the men (n=3) and partners (n=2) suggested the need to include HCPs in the study in order to explore findings in greater depth. For example, men's narratives around their healthcare experience indicated this significantly influenced their overall perception of their CaP experience. The men reported having unmet information and psychosexual support needs post-treatment and felt HCPs were unaware of such needs. Partners also reported a lack of recognition for their support needs by HCPs.

Some men's perceptions of subtle stereotypical behaviour from their HCPs also indicated a need to explore their (HCPs) own side of the story but research which had explored HCPs' views on this subject was found to be lacking. Evidence which associates racial discrimination in healthcare with poorer health outcomes among Black men has mostly been from patients' perspective on diabetes (Assari *et al.* 2017) and HIV/AIDs (Arnold *et al.* 2017). HCPs were rarely included in these studies. Hence, it was deemed necessary to follow this lead and explore HCPs' experiences of caring for BA/BC men with CaP and what they perceived as the men's support needs. The research objectives were subsequently modified to include this detail.

As discussions on recruitment of men were already ongoing with gate-keeping HCPs at the different NHS Trusts contacted, the idea of interviewing some staff within the uro-oncology team was discussed with them. The HCPs welcomed the idea and the study proposal was revised as appropriate for necessary ethical applications. This reflects the fluidity of grounded theory studies in which theoretical sampling has been known to have the potential to make changes to the initial line of enquiry (Charmaz 2014). Theoretical sampling did not change the entire course of this research but rather, it provided the guide necessary to ensure that the theory developed was grounded in participants' data, well conceptualised and saturation was achieved (Further detail on data saturation in section 3.3.7.4).

3.3.4.3 Screening for eligibility

Prior to sending them an information pack, potential participants who indicated interest in participating in the research were screened for eligibility in order to ensure that only participants who met the inclusion and exclusion criteria were eventually recruited into the study. This was done using a telephone screening protocol (Appendix 1) which articulated eligibility questions

based on the study's inclusion and exclusion criteria. The telephone screening protocol also detailed the steps to be followed in determining participants' eligibility to participate in the study and the required actions to be taken following confirmation of a potential participant's eligibility or otherwise. The telephone screening protocol was developed by the researcher in response to feedback from the ethics committee during the ethical application process. The protocol proved to be a useful tool in ensuring consistency in the eligibility assessment procedure and managing both the participant's and researcher's time at the initial stage of the recruitment process.

3.3.4.4 Participant information pack

Following confirmation of each potential participant's eligibility as detailed above, those who verbally expressed their willingness to participate in the research were asked to give the researcher their contact address details (postal or email address) for her to send them an information pack. Potential participants approached by gate-keeping HCPs at the NHS Trusts were also given an information pack by the HCPs. Men who had partners who were willing to participate in the study also provided their partner's contact details for the researcher to send the partner an information pack. The information pack consisted of: a participation letter to thank participants for their expression of interest and provide further information on next steps (Appendix 2); a participant information sheet (PIS) (Appendix 3) which explained the purpose of the study and what taking part would involve; a consent form (Appendix 4); and a pre-stamped addressed envelope to return their signed consent form to the researcher. As part of patient and public involvement (PPI) in the study, feedback regarding the suitability of the information sheet was elicited from a Black male in his fifties, the chairman of a prostate support group and gate-keeping HCPs at two of the NHS Trusts. They commented that the information

sheets were sufficiently detailed and understandable for lay participants. Once a signed consent form was received (either by post or email), the researcher contacted the participant again to agree interview arrangements. Further details on informed consent are presented under Ethical Considerations (section in 3.3.6.2). An overview of the study design is outlined in Figure 1.

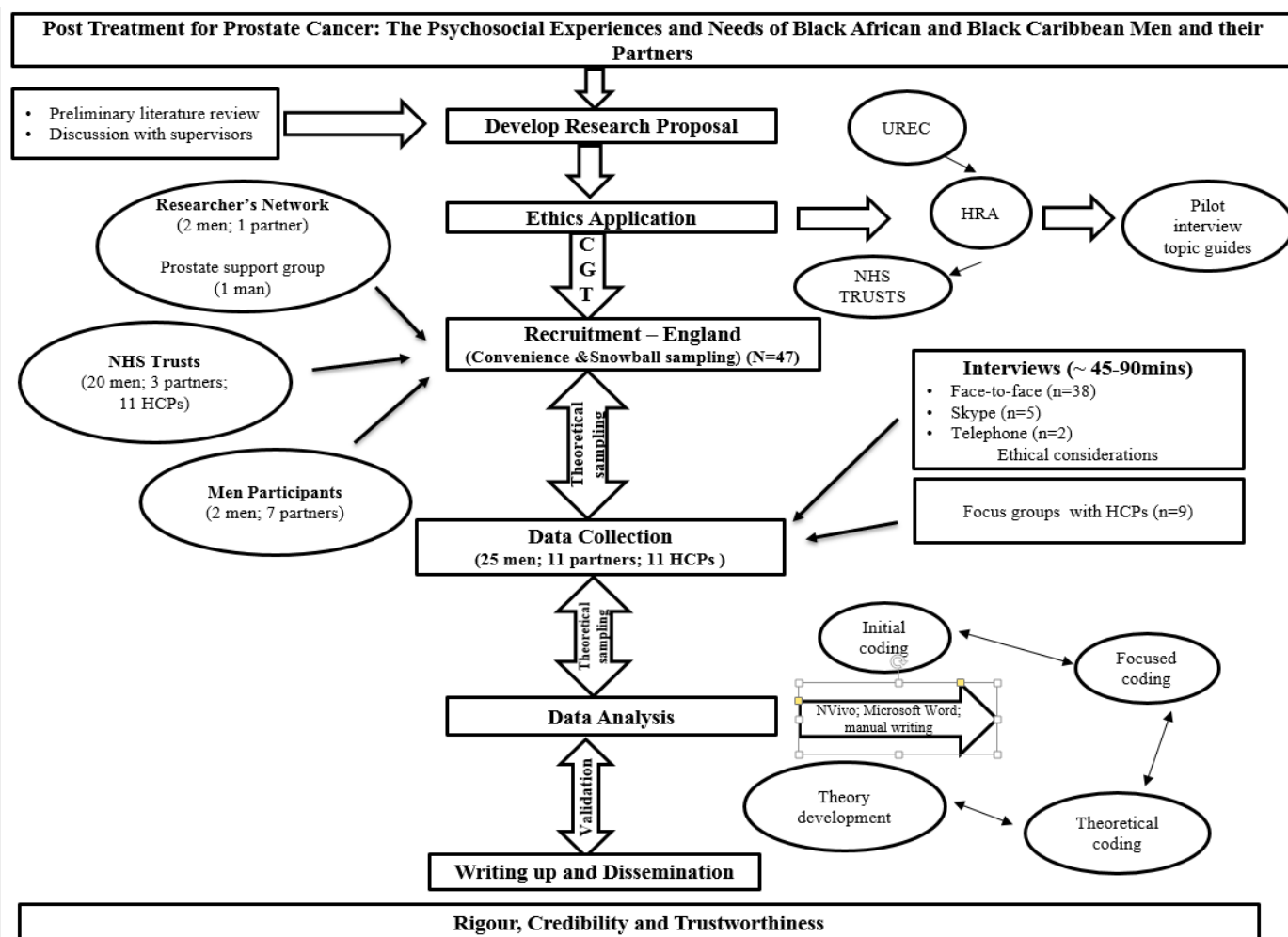





Figure 1: Overview of Study Design

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“Hard to reach, but not out of reach”: Barriers and facilitators to recruiting Black African and Black Caribbean men with prostate cancer and their partners into qualitative research

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Abstract

Access and recruitment barriers may have contributed to the underrepresentation of Black African/Caribbean men and their partners in current psychosocial research related to prostate cancer survivors. Whilst some studies have explored recruitment barriers and facilitators from participants' perspectives, little is known from researchers' point of view. This paper aimed to address this gap in the literature. Recruitment strategies included the following: cancer support groups, researchers' networks, media advertisement, religious organisations, National Health Service hospitals and snowball sampling. Thirty-six eligible participants (men = 25, partners = 11) were recruited into the study. Recruitment barriers comprised of gate-keeping and advertisement issues and the stigma associated with prostate cancer disclosure. Facilitators which aided recruitment included collaborating with National Health Service hospitals, snowball sampling, flexible data collection, building rapport with participants to gain their trust and researcher's attributes. Findings highlight that “hard to reach” Black African/Caribbean populations may be more accessible if researchers adopt flexible but strategic and culturally sensitive recruitment approaches. Such approaches should consider perceptions of stigma associated with prostate cancer within these communities and the influence gatekeepers can have in controlling access to potential participants. Increased engagement with healthcare professionals and gatekeepers could facilitate better access to Black African/Caribbean populations so that their voices can be heard and their specific needs addressed within the healthcare agenda.

KEYWORDS

African caribbean, Black African, men, partners, prostate cancer, recruitment

1 | INTRODUCTION

Prostate cancer (CaP) affects one in four Black African (BA) and Black Caribbean (BC) men earlier in life and in more aggressive forms

compared with one in eight Caucasian men (Jones & Chinegwundoh, 2014). However, it appears that access and recruitment barriers may have contributed to the underrepresentation of BA and BC men and their partners in current psychosocial research related to CaP survivors (Bamidele, McGarvey, et al., 2017) as these have mostly involved Caucasian (McCaughan, McKenna, McSorley, & Parahoo,

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2015; O'Shaughnessy, Ireland, Pelentsov, Thomas, & Esterman, 2013; Speer, Tucker, McPhillips, & Peters, 2017) and some African American (AA) (Rivers et al., 2011, 2012) groups.

The National Institute for Health and Care Excellence (NICE, 2015) recommends the provision of psychosocial interventions to complement clinical aids in supporting men after CaP treatment. Given the existing ethnic diversity of the UK population (Office for National Statistics [ONS], 2012), cultural disparities in CaP experiences and support needs as influenced by their specific socio-cultural context should be considered when developing psychosocial interventions for men with CaP and their partners (Hosseinpoor, Williams, Itani, & Chatterji, 2012; Marmot et al., 2010; Pinder, Ferguson, & Moller, 2016). Qualitative researchers in particular, have a role in helping to engage under-studied BA and BC groups in in-depth research to inform the provision of culturally sensitive psychosocial support for them after CaP treatment.

Amidst suggestions that BA and BC groups are often “hard to reach” (Mulugeta, Williamson, Monks, Hack, & Beaver, 2017) because they cannot be easily accessed by researchers (Sydor, 2013), there is a dearth of literature reporting researchers' perspectives on the barriers and facilitators to recruiting BA/BC men and their partners into qualitative research on CaP survivorship. Current available evidence has focused on participants' perspectives and clinical research on CaP (Toms, Cahill, George, & Hemelrijck, 2016). Wider evidence relating to other “hard to reach” groups further highlights that participants' opinions of the topic being investigated (Jones et al., 2014), and the nature of research being conducted (e.g.,

experimental studies) may also have an impact on recruitment outcomes (Mamotte & Wassenaar, 2017; Newington & Metcalfe, 2014). These suggest the need for qualitative researchers to be aware (through other researchers' experiences) of strategies they can adopt to maximise recruitment for their studies.

In light of the above, this paper aims to: (a) report the strategies used to recruit BA and BC men with CaP and their partners into a grounded theory study; (b) discuss the barriers and facilitators to recruitment; and (c) provide useful suggestions for other researchers seeking to engage similar groups and other “hard to reach” populations in their studies.

2 | METHODS

2.1 | The study

The main aim of the grounded theory study was to explore the experiences of BA/BC men and their partners and their psychosocial needs after CaP treatment and how best to address them. Participants were recruited in England which has a high BA and BC populations (ONS, 2012). Prior to theoretical sampling which is ideally used in grounded theory studies, convenience and snow-ball sampling were used to identify participants to generate the initial data. Upon receipt of ethical approvals, recruitment of eligible participants occurred between October 2016 and March 2018. Participants were provided with contact details of relevant support services if required. Upon providing written informed consent,

	Inclusion	Exclusion
Men	<p>BA or BC ethnic origin</p> <p>Undergone at least 3 months post active treatment for CaP</p> <p>Aged 35 years and above (BA/BC men may develop CaP earlier in life compared to men of other ethnic populations)</p> <p>Resident in the UK</p> <p>Able to read, understand and speak English language</p>	<p>BA/BC men receiving palliative care (because it was perceived that their needs may be beyond the scope of the study)</p>
Partners	<p>In intimate or marital relationship with a BA or BC man who has undergone at least three months post active treatment for CaP</p> <p>Resident in the UK</p> <p>Aged 18 years and above</p> <p>Able to read, understand and speak English language</p> <p>Can be of any ethnic origin</p> <p>Can be of any gender</p>	<p>Partners of BA/BC men with CaP receiving palliative care (same as reason for excluding the men)</p>

TABLE 1 Inclusion and exclusion criteria for the study

participants had the option to be interviewed either face-to-face, by Skype or telephone. The interviews, which were tape-recorded and lasted between 30 and 90 min, were conducted by the first author (OB) who is a BA woman in her mid-thirties. Where a man and his partner agreed to be interviewed, in an attempt to keep both engaged in the study, interviews where possible, were scheduled for the same date and mode. This also helped the researcher to manage her time and financial resources. The partners were interviewed separately.

2.2 | Study sample

Three different sample groups were included in the study: (a) BA and BC men with CaP; (b) partners of BA or BC men with CaP; and (c) healthcare professionals (HCPs) within an uro-oncology team. This article focuses on the recruitment of BA/BC men with CaP and their partners. Recruitment was guided by pre-defined inclusion and exclusion criteria (Table 1). Eligible partners were included irrespective of their gender or ethnicity (self-reported). Partners' inclusion was not dependent on their male partners with CaP participating in the study.

2.3 | Recruitment strategies

Although priority in qualitative research is focused more on obtaining rich and in-depth data, (Bonevski et al., 2014), it was considered essential to reduce the risk of under-recruitment which could jeopardise theoretical saturation (when emerging categories are fully conceptualised and no further data is required) crucial to the rigour and trustworthiness of this grounded theory study (Foley & Timonen, 2015). Therefore, the research team projected (based on previous grounded theory studies e.g., Mulugeta et al., 2017) that approximately 30 men and partners inclusive, would provide the rich in-depth data required to achieve theoretical saturation. We also considered that the few previous related studies (Anderson, Marshall-Lucette, & Webb, 2013; Gray, Fergus, & Fitch, 2005; Nanton & Dale, 2011) had mostly involved Jamaican men and no study was identified which included partners of BA/BC men with CaP. Thus, we decided to diversify recruitment strategies to enhance recruitment of a more heterogeneous sample of eligible BA/BC men and also partners into the study.

Ideas about recruitment were deliberated among the research team, explored with other researchers who have had success with recruiting Black men with CaP into their studies (e.g., Nanton & Dale, 2011), and also discussed with a Patient Public Involvement (PPI) group. The PPI group consisted of a female uro-oncology nurse specialist, a male leader of a prostate cancer support group and a BA man with CaP in his early fifties. Potential recruitment strategies were identified which included cancer support groups, colleagues' and researchers' networks, media advertisement, religious organisations, National Health Service (NHS) hospital Trusts and snowball sampling via research participants.

2.3.1 | Cancer support groups

A total of 33 support groups which focused on Black and Minority Ethnic (BME) cancer survivors were identified and contacted by the researcher (OB) either by email or telephone. The nature and process of the study were clearly explained to a lead contact within each support group. Their role in helping to facilitate access to eligible members and the potential value of the research to their organisation and BA/BC service users were also clarified to the support groups. The lead person or an identified gatekeeper at each support group was asked how best to access and recruit any eligible members for the study. A poster was developed by the research team to advertise the study at the support groups. Feedback from gatekeepers at support groups was invited as regards the suitability of the poster, especially in terms of content, language use and comprehensibility. In line with the approved study protocol, gatekeepers who were willing in the first instance were asked to discuss the study with interested eligible members. This was to try and help establish trust and develop a rapport with the potential participant (Anderson et al., 2009). If a member of the support group agreed, their contact details were passed on to the researcher (OB) for further discussion. Eligible potential participants were then sent an information pack detailing the purpose of the research, what their participation would involve and contact details of the researcher. Once a participant who was happy to take part returned his signed consent form, interview date, time and venue were agreed.

2.3.2 | Colleagues' and researchers' network

A network of colleagues and researchers who had previously published in related fields were contacted and asked to suggest possible avenues to explore recruitment. Any contacts who were aware of potential participants discussed the study with them initially and with their permission, forwarded their contact details to the researcher. The researcher then made direct contact with the potential participant and following consent, scheduled an interview.

2.3.3 | Media advertisement

Using a tailored media script, the study was advertised on two UK-based radio stations located in London and Birmingham and focused on BA and BC audiences. Radio presenters from both stations suggested appropriate presentation styles that they perceived would appeal to the Black population (e.g., having low background music and a Black male narrator). The advertisement ran on each of the two radio stations approximately eight times daily for a month and also on their websites, at a total cost of £505. Due to limited finances, it was not possible to extend the advert beyond a month or to other radio/TV stations or newspapers.

TABLE 2 Recruitment strategies and outcomes

Recruitment strategy	Potential contacts received <i>n</i>	Successfully contacted to take part <i>n</i> (%)	Identified as ineligible <i>n</i> (%)	Declined to participate <i>n</i> (%)	Men who participated <i>n</i> (%)	Partners who participated <i>n</i> (%)	Overall total participants (men and partners) <i>n</i> (%)
NHS Trusts	38	32 (71)	3 ^a (7)	6 ^b (13)	20 (80)	3 (27)	23 (64)
Snowballing using recruited research participants	10	9 (20)	–	–	2 (8)	7 (63)	9 (25)
Colleagues and Researchers' Networks	3	3 (7)	–	–	2 (8)	1 (9)	3 (8)
Cancer support groups	1	1 ^a (2)	–	–	1 (4)	–	1 (3)
Media advert	–	–	–	–	–	–	–
Religious organisations	–	–	–	–	–	–	–

^aYet to undergo active treatment; on active surveillance. ^bLack of time; personal reasons; no reason.

2.3.4 | Religious organisations

In light of the high rate of those who attend church services within the Black community (Akhazemea, 2015; TEARFUND, 2007), the church was also considered as a potential avenue to access participants for the study. The leaders of three churches (same denomination but located at different areas with dense Black populations across England) were contacted to discuss the possibility of recruitment within their congregation. Using a poster, church leaders were asked to help create an awareness about the study. The option of having the researcher come and introduce the study to their congregation was also discussed. Despite these approaches, efforts to pursue recruitment further after these initial discussions proved difficult.

2.3.5 | National health service hospital trusts

Recruitment was further explored by collaborating with three NHS hospital Trusts based in London. A consultant urological surgeon, an uro-oncology clinical nurse specialist and research nurses who cared for patients with CaP all helped to expedite access to potentially eligible patients at their respective hospitals. Following ethical approval, the HCPs at each of the hospitals made the initial contact with eligible patients and provided the study information sheet. The consent procedure for eligible patients was agreed with each of the HCPs in line with their Trust's internal procedures and policies.

2.3.6 | Snowball sampling

Participating men who had partners were asked to help inform them (partners) about the study or with their partners' permission, the researcher contacted them directly to discuss the study. The participating men were also asked to refer any other known eligible BA/BC men with CaP to the researcher. Although some participants knew about other potentially eligible men, they stated they could not refer

them to the study because they did not want to disclose their own illness to others and mentioning the research to them (potential participants) could compromise this stance.

3 | RESULTS

3.1 | Overview

A detailed description of our recruitment strategies and outcomes is presented in Table 2. The contact details of 52 potential participants (men = 41; partners = 11) were received across the various recruitment strategies. From these, 45 participants (men = 34; partners = 11) were successfully contacted. Seven men could not be contacted because they were unreachable by phone and did not respond to the invitation letter and information pack sent by post. Three men with CaP were deemed ineligible (two were on active surveillance and it was less than three months since one had undergone active treatment) whilst six declined to participate. In total, 36 eligible participants (men = 25, partners = 11) agreed to participate in the study and were interviewed. The demographic details of participants are presented in Table 3. The majority of the participants preferred face-to-face interviews (*n* = 29, 81%). Due to geographical and time limitations, two participants (man and partner) were happy to be interviewed by telephone whilst the remaining five were interviewed by Skype. Participating in a qualitative study was a new experience for the majority of the men and partners and many of them viewed their participation as an avenue to share their experiences to "help others" on their CaP journey.

3.1.1 | Reasons given for non-participation

For those six men who declined to participate, none expressed any ethical concerns regarding the conduct of the study. Two men were unable to find time for a face-to-face interview and were not willing to consider a telephone or Skype interview. Although three men did

not formally decline participation, after few unsuccessful attempts at contacting them, their silence was taken as a refusal and no further contact was made. One participant gave personal reasons for declining to participate and his decision was respected.

3.2 | Recruitment outcomes

The projected sample size of 30 participants was exceeded and theoretical saturation was achieved. However, some strategies were more successful than others for recruiting participants into the study. Although statistical analysis was not conducted to measure the effectiveness of each strategy, it was considered necessary to highlight how they individually contributed towards recruitment. We defined strategies which mostly contributed towards the achievement of our recruitment target as successful whilst those which recruited only one or no participant at all were regarded as unsuccessful.

3.2.1 | Successful strategies

Collaborating with NHS hospital Trusts and snowball sampling were the most successful strategies, yielding 64% ($n = 23$) and 25% ($n = 9$) of the total participants recruited respectively (Table 2). For the men group, the majority (80%) were recruited through the three NHS hospitals whilst the majority of partners (63%) were recruited by snowball sampling through their participating husbands (Table 2). Two men were also recruited by snowballing through their friends who had already participated in the study. Colleagues, and researchers' networks also yielded three participants (men = 2, partner = 1).

TABLE 3 Ethnic representation of study participants

	Men <i>n</i> (%)	Partners <i>n</i> (%)
Black African (11)		
Nigeria	2 (8)	1 (9)
Ghana	4 (16)	2 (18)
Sierra Leone	2 (8)	–
Black Caribbean (21)		
Jamaica	8 (32)	2 (18)
Barbados	4 (16)	2 (18)
Guyana	1 (4)	–
Montserrat	1 (4)	–
St. Lucia	1 (4)	–
Caribbean Virgin Islands	1 (4)	–
Dominica	1 (4)	–
White (4)		
British	–	2 (18)
Irish	–	1 (9)
Spanish	–	1 (9)
Total ($n = 36$)	25 (69)	11 (31)

3.2.2 | Unsuccessful strategies

Despite contacting 33 support groups, only one man was recruited into the study via this strategy (Table 2). No partner was identified nor recruited from the support groups. The researchers' experience with the support groups showed that although some gatekeepers were willing, others were less enthusiastic in enabling access to potentially eligible members within their group. Some were slow to respond to emails or phone calls, and some requested non-negotiable and/or substantial payment as a prerequisite for informing their members about the research. Such payment demands could not be met due to limited finances available for this research. The media advertisement and religious organisations did not yield any eligible participants for this study. It had been anticipated that the first author's personal network with religious leaders could yield potential eligible members of their churches, but such attempts were not successful. After the initial face-to-face discussions, there were long delays in responding to follow-up emails and telephone calls.

4 | DISCUSSION

Recruitment outcomes varied among the different strategies used to recruit 'hard to reach' BA and BC men with CaP and their partners into this qualitative study. The barriers and facilitators to successful recruitment of participants for this study will now be discussed.

4.1 | Barriers

In addition to a few participants declining to participate for reasons highlighted earlier, additional barriers were encountered which limited recruitment for this study. These are categorised as actual and perceived barriers. Actual barriers were those encountered during fieldwork for this study and included "gatekeeping issues" and "stigma associated with prostate cancer disclosure." The perceived barrier was the researchers' perception of an additional limitation to recruitment as informed by a reflection on our recruitment experience. This included "limited advertisement."

4.1.1 | Gatekeeping issues

Similar to findings from a review by Bonevski et al. (2014), gatekeeping emerged as an actual barrier to recruiting participants from the support groups and religious organisations approached. Gatekeepers at many of the support groups and religious organisations restricted access to potentially eligible members. As a result, members did not have the opportunity to make their own decision about participating. Where men were the gatekeepers to accessing their partners, some declined their partner's participation noting that the women preferred to "operate behind the scene" than engage in research participation. Hence such men did not give their partners the opportunity to make their own informed decision to participate or not.

Whilst acknowledging the autonomous power of gatekeepers at support groups and religious organisations to either hinder or promote access to their members or contacts (Singh & Wassenaar, 2016), there is need to also consider how this may possibly impact on the voluntary rights of potential participants to personally decide their participation or otherwise in a research study (Mamotte & Wassenaar, 2017; Wanat, 2008). Experience with participants in this study suggests that they may be willing to participate in research studies if they are asked, as many of them seemed to view their participation as a way of “helping others.” Although the researcher offered to volunteer at one of the support groups approached and all the support groups were also told they would be provided with summary of research findings as an “incentive” for their cooperation (Singh & Wassenaar, 2016), this strategy remained unsuccessful for the current study.

Some gatekeepers at support groups with high BAs/BCs were also unwilling to inform their members about the study unless the researchers met certain prerequisite payment demands to cover interviewing costs and provide incentives for participating members. Such payment demands could not be met due to limited funds available to complete this academic research. The researcher also clarified to the gatekeepers that participants would not be burdened with travel or financial costs as the researcher would meet with them at their preferred location. However, such explanations were not productive. Debates exist regarding the ethical implications of incentivising research participation on participant's autonomy (Collins et al., 2017; Polacsek, Boardman, & McCann, 2017). Whilst some studies (Faseru et al., 2010; George, Duran, & Norris, 2014) have reported giving of incentives encouraged research participation among their African American participants, others argued (Toms et al., 2016) that incentives may be perceived as suspicious and debar BA and BC men with CaP from participating in clinical research. Rivas, Kelly, and Feder (2013) suggest that informing participants of incentives at their interviews, without any prior knowledge could help reduce suspicion and potentially encourage voluntariness in research participation. Since potential participants at support groups were not informed about the study, it is unclear how incentivising the research may have influenced their personal decision to participate in this qualitative study or not. Arguably, some gatekeepers may be regarded as having an experiential understanding of how best to engage their members in research participation. However, there is need to consider the peculiar nature of each study and allow members the personal autonomy to accept or decline research invitations regardless of the presence or absence of financial incentives.

Previous studies involving Black populations (e.g., Nanton & Dale, 2011; Bamidele, Ali, Papadopoulos, & Randhawa, 2017) had successfully recruited participants through religious settings. However, it appeared because of other duties taking precedence, discussing the study among their congregational members was not viewed as a priority for the church leaders who were approached. It was also perceived that the delicate nature of being diagnosed with CaP may have further contributed to the church leaders' reluctant attitude towards this study. Prior evidence (Sheikh et al., 2009) suggested a

gap in knowledge among religious leaders regarding the importance of research and their influence in encouraging research participation among their members. It is envisaged that better outcomes may have been achieved if recruitment was explored across different religious settings (e.g., other churches, mosques) and denominations over a longer period of time, but this could not be achieved in the current study due to a limited time frame.

4.1.2 | Stigma associated with prostate cancer disclosure

Some participants' (men) reluctance to refer other eligible men to the study was an actual barrier to recruitment. The men attributed this to protecting non-disclosure of their CaP diagnosis within their wider social circle (including friends and religious affiliations). Non-disclosure was mostly attributed to perceptions of self and social stigma associated with being diagnosed with CaP within the BA/BC cultural setting. This supports existing evidence that cultural perceptions of CaP (such as fatality, emasculating) often impact on Black men's attitudes and behaviours towards public disclosure of the disease (Kendrick, 2010; Mulugeta et al., 2017; Pedersen, Armes, & Ream, 2012; Rivas et al., 2016). Nevertheless, Nanton and Dale (2011) successfully recruited Jamaican men with CaP through the church, personal contacts of their interviewers and the local community. Conflicting recruitment outcomes between this current study and Nanton and Dale's (2011) suggest that similar strategies may not necessarily generate the same outcomes even for similar studies and target populations.

4.1.3 | Limited advertisement

Recruitment through media adverts was perceived to have been impeded by limited advertisement as the research was advertised on only two radio stations for one month. This was substantially due to financial constraints to cover the associated costs of extending advertisement to other media channels with wider coverage areas and for much longer. Upon reflection, it was perceived that complementing extensive radio advertisement with other media channels such as television, newspapers with a wider focus on Black audience may have improved our recruitment outcome via this strategy (Graham, Lopez-Class, Mueller, Mota, & Mandelblatt, 2011), especially from within the community.

4.2 | Facilitators

Recruitment success was aided by a number of factors which were also classified as actual and perceived facilitators. The actual facilitators which emerged from fieldwork as informed by our recruitment outcomes included “collaborating with NHS hospital Trusts,” “snowball sampling” and “flexibility in data collection modes.” Upon reflection on our experience during fieldwork, recruitment also seemed to have been facilitated by “building rapport with participants to gain their trust” and “researcher's attributes.”

4.2.1 | Collaborating with National Health Service hospital Trusts

Consistent with the study of Anderson et al. (2013) in which all their BA and BC participants were recruited through the hospital, collaborating with NHS hospitals emerged as the most successful strategy for recruiting men into this study as 80% of them were recruited via this means. Lyons et al. (2013) suggested that using gatekeepers with whom participants are familiar could improve access to culturally diverse populations. HCPs' goodwill and rapport with their patients further enhanced recruitment in the current study as some participants spontaneously commented on these during their interviews. Patients being reassured by a HCP that the study had received ethical approval and that participation would not affect their care in any way, may have promoted men's confidence in the authenticity of the research (Anderson et al., 2009). Although complex ethical application processes often limit researchers' abilities to access "hard to reach" patients within limited time and financial resources, the interest and support shown by the HCPs facilitated the process of seeking ethical approval. To retain the interest and support of the HCPs, they were constantly updated on the progress of the study.

4.2.2 | Snowball sampling

Using snowball sampling facilitated recruitment of partners into the study. The majority of partners (63%) were recruited through their participating husbands. Snowball sampling thrives on the use of personal relationship networks to access participants who otherwise may not have been aware of, or participated in a study (Etikan, Alkassim, & Abubakar, 2016; Wohl et al., 2017). Although prone to selection bias which may result from over-representation of members of a particular participant's network (Etikan et al., 2016), snowball sampling has been widely acknowledged as useful in promoting research participation among "hard to reach" populations in a cost-effective and timely manner (Richards & Morse, 2007; Sadler, Lee, Lim, & Fullerton, 2011; Wohl et al., 2017). Nanton and Dale (2011) successfully used snowball sampling to recruit African-Caribbean men with CaP ($n = 16$) into their qualitative study. Whilst this strategy enhanced successful recruitment in their study, it appeared to have contributed to the selection bias observed in the study leading to a homogenous sample of Jamaican men (Nanton & Dale, 2011). The risk of selection bias often associated with snowball sampling was minimised in this study by complementing it with additional recruitment strategies (Etikan et al., 2016).

4.2.3 | Flexibility in data collection mode

As similarly reported by Shedlin, Decena, Mangadu, and Martinez (2011), using flexible data collection modes also enhanced recruitment for this study. Participants had options to be interviewed either face-to-face, by telephone or via Skype. The majority of participants ($n = 29$; 81%) preferred to be interviewed face-to-face in their natural environments (homes and private office). Interviewing participants

in their own familiar and relaxed environments enhanced data collection and without them experiencing any travel or financial burden (Bryman, 2012). Noting the perceived delicate nature of their illness experiences, especially where there would be discussions around sexual function (Anyan, 2013; Szolnoki & Hoffmann, 2013), it was understandable that the majority of our participants preferred face-to-face interviews.

Given the distant geographical location of some participants, they opted to be interviewed by Skype when offered. With improvements in technology, Skype interviews now provide a useful alternative to face-to-face interviews by helping to bridge distance barriers, reduce travel risks and minimise costs (Deakin & Wakefield, 2014). Although evidence shows that Skype interviews could be prone to technological distractions, less rapport building and reduced clarity in audio-recordings which could impact on data quality (Janghorban, Latifnejad, & R. and Taghipour, A., 2014), it was used successfully in this study. Having a video facility within Skype was also useful to help to capture non-verbal clues during the interviews (Janghorban et al., 2014). Likewise, potential undesirable technological interferences and poor audio recording quality which could occur during Skype interviews were mitigated by the researcher's and participants' familiarity with technology and by ensuring that interviews were scheduled for times and places with uninterrupted Internet access (Deakin & Wakefield, 2014). Where acceptable by their participants, future studies may also explore the use of Skype as a proficient alternative to overcome cost and distance barriers associated with face-to-face interviews. This could help ensure that participants recruited into the study are promptly interviewed without jeopardising rapport building.

4.2.4 | Building rapport with participants to gain their trust

Establishing trust with potential participants through rapport building was perceived to also have enhanced successful recruitment for this study. To facilitate rapport, the same researcher (OB) followed them from recruitment to conducting their interviews. This seemed to help create a sense of familiarity with participants and encouraged a high retention rate as all the participants recruited were successfully interviewed. There were also indications that using face-to-face interviews, coupled with the interviewer's (OB) ethnicity as BA may have further enhanced rapport building with study participants as many of them seemed to identify with her as an "insider" (Fassinger and Morrow (2013). Some studies highlight the importance of ethnically matching interviewers with ethnic minority participants as a way of showing cultural sensitivity and promoting shared identity to improve research engagement with them (Anderson et al., 2009; Nanton & Dale, 2011; Rugkåsa & Canvin, 2011). However, relevant theories such as the intersectionality theory (Crenshaw, 1989) argue that study participants' perceptions of the researcher as either an "insider" or an "outsider" is oftentimes not solely influenced by a shared cultural identity related to race and ethnicity only, but by an intersection between these factors (race

and ethnicity) and other wider factors such as gender, age and sexuality. Katigbak, Foley, Robert, and Hutchinson (2016) also insist that shared ethnicity between researchers and their study participants does not necessarily imply shared experience. Nash (2008) further identified the importance of the intersectionality theory in facilitating a conceptual understanding of the complexities around “insider/outsider” status in research relationships especially when studying marginalised populations.

4.2.5 | Researcher's attributes

Evidence suggests that the researcher's attributes could impact on recruitment and research participation especially among BME populations (Hoppitt et al., 2012; Sheikh et al., 2009). It had been anticipated that the researcher's gender and age as a young female in her mid-thirties may have potentially imposed an “outsider” status which could limit recruitment and quality data collection from older BA/BC men on a sensitive male-focused subject such as CaP (Braun & Clarke, 2013; Khambhaita, Willis, Pathak, & Evandrou, 2017). However, none of the study participants expressed any concerns regarding this as they freely shared their stories (including the “sensitive” sexual aspects of their experiences).

This resonates with evidence from previous studies which had successfully used female researchers to interview Caucasian (McCaughan et al., 2015) and Black (Anderson et al., 2013) men with CaP. Fergus, Gray, and Fitch (2002) highlighted that most of the male participants in their study expressed preference to be interviewed by a female researcher when they were offered choices between a male or female interviewer. This suggests that the researcher's gender or age may be less important in research relationships with Black men with CaP especially where such researchers are experienced in conducting qualitative interviews. Moreover, complementing her previous experience of successful research engagement with BA populations with her ethnicity as BA enhanced the researcher's ability to build mutual understanding with study participants. The PPI group also suggested that providing information to participants to aid their understanding of the purpose of the scientific study has the potential to reduce barriers associated with gender differences between a female researcher and male study participants.

4.3 | Implications for practice

The recruitment challenges experienced in this study are not peculiar to BA and BC men with CaP and their partners. Previous research which involved other “hard to reach” (e.g., victims of abuse [Rivas et al., 2013]) and vulnerable populations (e.g., people with a learning disability [Carey & Griffiths, 2017]) have reported similar challenges when trying to recruit participants. However, findings from this study highlight that amidst shared similarities in recruitment barriers, there is no “one size fits all” approach to navigating such challenges. There is need for researchers to be dynamic and understand the specific characteristics of their target populations

whilst considering the nature of their research in order to tailor their recruitment approaches. For example, the perceptions of stigma associated with CaP within the BA and BC communities which impact on their attitude towards their illness disclosure highlight the importance of involving their healthcare providers in the recruitment plan for this study. In addition to gatekeeping issues when recruiting BA/BC men with CaP and partners, due considerations should also be given to time and cost implications. Furthermore, there is need for researchers to respect the terms and conditions stipulated by support groups to access their members. For example, physically meeting with gatekeepers and fulfilling stipulated payment demands may have advanced better recruitment outcomes from the support groups contacted in this study. Nevertheless, it is essential that researchers remain realistic in their recruitment expectations in terms of the number of participants they can recruit within the allocated resources for a study. Gatekeepers at support groups also need to be aware of the ethical implications of withholding research information from their members and how this may potentially contribute to their (members') marginalisation in emerging evidence. It is essential that gatekeepers ensure that their members are given an opportunity to make their own decision regarding participation in studies once ethical considerations have been applied. Whilst the religious organisation approached for this study was not particularly productive for recruitment, prior evidence highlights that religious organisations continue to be potential avenues for recruiting Black populations into research studies (Bamidele, Ali, et al., 2017; Nanton & Dale, 2011). Researchers should continue to engage with religious leaders, increasing their awareness on the potential benefits of research participation and encourage their cooperation in helping to enable access to interested and eligible members where appropriate. Evidence from this study supports previous suggestions (Newington & Metcalfe, 2014) that research participation can be enhanced if patients are informed about the study by their main HCPs. This further suggests the need for future researchers to continue to liaise with HCPs who are the men's primary care givers in order to improve recruitment outcomes for their studies.

4.4 | Study limitations and directions for future research

In contrast to previous related studies (Anderson et al., 2013; Nanton & Dale, 2011), the recruitment of a more heterogeneous sample of “hard to reach” BA/BC men with CaP into the current study was facilitated by collaborating with NHS hospital staff. Recruitment of partners was also enhanced by snowballing through their husbands who participated in the study. However, the actual response rate for the study could not be assessed because the overall number of participants who were approached were not recorded by the HCPs (e.g., potential participants who may have possibly declined participation at the point of being informed about the study by an HCP without the researcher receiving their contact details). Although statistical calculations such as response rates are less significant in qualitative studies like this, we

acknowledge that the success or otherwise of the different strategies used are subjective to our particular recruitment experience and cannot be generalised. Future papers on recruitment should endeavour to apply statistical measures to their response rates in order to enhance a more rigorous assessment of their recruitment outcomes, especially for larger quantitative studies. Future studies could also explore from gatekeepers' perspectives, their experiences with researchers and the challenges of promoting research participation among their BA/BC members. This could help to provide a more balanced understanding of recruitment challenges and how such can be more effectively addressed in order to improve research engagement with "hard to reach" groups.

5 | CONCLUSION

Little is known from the researcher's perspective about the barriers and facilitators to recruiting high risk yet under-researched BA and BC men with CaP and their partners into qualitative research. This paper has contributed towards reducing this knowledge gap. Collaborating with NHS hospital Trusts and snowballing through participating men were the most successful strategies for recruiting men and partners respectively into this study. Support groups, media advertisement and religious organisation were less successful recruitment strategies. Researchers' experiences in this study indicate that BA and BC populations may be "hard to reach" but they are not "out of reach" if flexible, strategic and culturally sensitive recruitment approaches are used.

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3.3.5 Data collection

Data were collected primarily using individual interviews. Decisions regarding choice of interviews were guided by the CGT design, sensitive research topic, 'private' nature of BA and BC groups, logistic reasons and ethical considerations for research participants' confidentiality (Bryman 2015). Interviews have also been adjudged as the most appropriate method of data collection in grounded theory studies as they facilitate going back and forth between data collection and analysis until the emerging theory is saturated (theoretical sampling) (Creswell 2007; Straus and Corbin 2008; Bryman 2015). Considerations for the busy schedule of HCPs and logistic reasons informed the decision to complement the HCPs' interviews with focus groups without jeopardising methodological congruence in CGT (see details at section 3.3.5.4). Prior to conducting the interviews and focus groups, topic guides were developed to guide the discussions.

3.3.5.1 The topic guides

In order to maintain focus on the purpose of the study, stimulate discussions and facilitate coherence in data collection procedures, semi-structured topic guides were used (Appendices 5 and 6). The topic guides contained open ended questions which allowed participants to direct the interviews whilst the researcher followed emerging leads but still ensured focus on the research aims and objectives. The initial open-ended questions were broadly framed around the study's objectives (informed by gaps in the literature and the study's aims). For example, the study's first objective was to investigate the experiences of BA and BC men with CaP and where applicable also the experiences of their partners respectively. This informed the first question on the topic guide for the men 'tell me about your prostate cancer experience' and for the partners 'tell me

about your experience of being a partner to someone diagnosed and treated for prostate cancer'.

The topic guides were piloted before the main data collection (see section 3.3.5.2). After the main interviews commenced, the topic guides were iteratively modified to explore emerging themes in greater depth (Charmaz 2014; Foley and Timonen 2015). See section 3.3.4.2 on theoretical sampling.

3.3.5.2 Piloting of topic guides

To validate the topic guides prior to the main interviews with the men with CaP and partners, they were piloted (Doody and Noonan 2013) with supervisors and a male cancer survivor in a role play semi-structured interview. During the pilot, it was observed that although the content of the topic guides seemed appropriate, there was need to modify the approach used for conducting the interviews. For example, demographic details preceded the main questions in the initial topic guide but it seemed to be too abrupt to delve into participants' personal details without first building rapport. Feedback from the pilot participants also indicated that questions regarding the impact of the CaP on their sex lives were perceived as too personal early in the interview and there was a reluctance to share. However, starting gradually from a broader, less sensitive subject like 'tell me about your prostate cancer experience' or 'tell me about your experience of being a partner to someone diagnosed and treated for prostate cancer ' (for the piloting partner) and highlighting that the participant could start from the aspect of his/her journey he/she felt comfortable to share, was a much better approach. This seemed to help the participant relax more and by the time the interview had progressed, the sensitive topics became more spontaneous and the researcher could probe further where necessary. The structure of the pilot topic guides was then modified accordingly before the main data collection for the study.

The modified topic guides were also presented to the study's PPI group (mentioned earlier) to elicit their views regarding the length and structure of the interviews. They commented that the structure of the topic guides and proposed time range of between 30 and 90 minutes for each interview seemed appropriate.

Using theoretical sampling also helped to improve the validity of the topic guides as they were iteratively modified based on emerging themes from interviews as data collection progressed (Charmaz 2014) (see appendices 5 and 6). The topic guide for interviews and focus groups with HCPs was also developed from emerging themes from the men's data in line with theoretical sampling conventions (Charmaz 2014). See details in section 3.3.4.2.

3.3.5.3 Interviews with men and partners

The researcher was aware of the 'private' nature of the study population and also carefully considered that discussing a sensitive topic with them in a group setting would be undesirable (Singh and Wassenaar 2016). Therefore, individual one to one interviews were deemed more appropriate to collect data. Debates exist among different grounded theorists regarding the interview process. Whereas Glaser (2007) in his classical version suggests the use of unstructured interviews as a means of ensuring 'grounded theory', Charmaz (2014) insists on the use of a semi-structured topic guide containing open-ended questions to facilitate co-construction of knowledge between researcher and participants without compromising on 'grounded theory'. Charmaz (2014) further asserts that using semi-structured interviews could enhance participants' freedom to direct the discussions, whilst the researcher still has the flexibility to gather rich and in-depth data to address the study's aim and objectives. This strength of semi structured interviews has also been identified to help reduce undesirable power

imbalances between the researcher and participant during the data collection process (Fasinger and Morrow 2013). As this study was underpinned by CGT and for the reasons highlighted above, semi-structured interviews were used (Ryan *et al.* 2009; Power *et al.* 2010; Holloway and Wheeler 2016). To prepare for the interviews and improve the researcher's theoretical sensitivity, she attended refresher training courses on qualitative interviewing and conducted pilot interviews (see section 3.3.5.2).

Eligible men and partners who consented to participate in the study were interviewed by the researcher either at their homes, place of work, by Skype or telephone. The interviews generally lasted between 30 – 90 minutes and were audio- recorded. Where couples participated in the study, the researcher discussed the option of interviewing them separately in order to facilitate openness and freedom of expression from both participants (Norlyk *et al.* 2016). Moreover, the goal of the research was to explore their perspectives as individuals and not shared experiences as dyads (Norlyk *et al.* 2016). All the participating couples agreed with this arrangement as they also acknowledged that they would feel more comfortable being interviewed alone compared with having their partners around. To enhance building of rapport and trust with participants, the researcher adopted a conversational style (Charmaz 2014) and started off with exchanging pleasantries with them and giving them some background information about herself and the study. By the time the main interview started, it was almost like chatting with a 'friend' (researcher's perception) or 'daughter' (researcher's perception of interview with the elderly participants) and the participants seemed comfortable to share their stories. Adopting a conversational style of interviewing also facilitated co-construction of knowledge regarding the study phenomenon as the both researcher and participants actively engaged in the interviews. To avoid repetition, further details on data collection for men and partners are discussed in **Paper 2**.

The researcher's reflections on the recruitment and data collection processes are also discussed in **Paper 2**.

3.3.5.4 Interviews and focus groups with healthcare professionals

In addition to using interviews, two focus groups were conducted with consenting HCPs at their respective NHS Trust premises. Taking into consideration the busy work schedules of potential participating HCPs and the less sensitive topic to be discussed, it was perceived that complementing the interviews with focus groups would enable the collection of quicker but rich, in-depth and contextualised data through group interactions and reflective discussions (Bryman 2015). Also noting the different areas of specialisation represented within the uro-oncology team (see Table 2), using focus groups enabled data triangulation within a wider range of perspectives at the same time and generated richer data which enhanced the rigour and trustworthiness of emerging categories (Noble and Smith 2015). Lasting between 30-45 minutes, the focus groups were held between June and August 2017 and were audio-recorded. One of the focus groups was co-facilitated by the researcher and her lead supervisor whilst the second focus group and individual interviews were facilitated by the researcher's lead supervisor. This was due to logistic reasons in accommodating participants' preferred date and time to be interviewed. For example, the researcher had to interview some men and partners on the same day when the HCPs were available to participate in the study and attending both or trying to reschedule without losing the participants was not practicable. However, all recruitment processes and scheduling of interviews were completed by the researcher. The demographic details of each participating HCP were collected at the end of the interview or focus group discussions. The interviews/focus groups were guided by a semi-structured topic guide with open ended questions (Appendix 7)

which were informed by emerging concepts from preliminary analysis of the men and partners' data (see details at section 3.3.4.2 on theoretical sampling).

3.3.6 Ethical considerations

CGT is not excluded from existing debates around power imbalances between researchers and their participants in which the latter have been previously perceived as taking a subordinate position to the former (Mills *et al.* 2006; Zou *et al.* 2014). To address such power imbalances, Anyan (2013) suggests that measures should be taken to promote a more reciprocal relationship between the researcher and study participants. This was achieved in this study through researcher reflexivity (self-awareness) in which the researcher had earlier clarified her underlying philosophical assumptions (see section 3.2). The researcher further declared no conflicting interest in the research and tried to maintain an open mind in data collection (using open ended questions) and analysis (taking data back to participants through theoretical sampling) such that the emerging theory was participant-focused and directed. There was mutual respect and relational engagement with participants through active communication and informed consent procedures (see section 3.3.6.2). Participants were also engaged in the decision-making process regarding if, when, where and how to be interviewed. This enhanced rapport building and seemed to have contributed towards successful data collection (Fasinger and Morrow 2013). Necessary ethical considerations were also duly observed and are discussed below.

3.3.6.1 Ethical approval

The University Policy for the Governance of Research Involving Human Participants (Ulster University 2015) and the Declaration of Helsinki (WHO 2001) guided the conduct of this

study. Ethical approvals were received from Ulster University Research Ethics Committee (UREC) (Appendix 8), the Health Research Authority (HRA) (Appendix 9) and each of the participating NHS Trusts (Appendix 10). Prior to receiving ethical approvals, the study protocol was peer-reviewed and comments from reviewers were addressed. For example, one of the feedback suggestions received from peer-reviewers was the need to develop a distress protocol (Appendix 11) detailing the process to be followed should a participant get upset during the interviews. A distress protocol was subsequently developed which included safeguarding information and reference to a list of available counselling services that participants could be signposted to if necessary. However, no participant expressed any distress nor concern before, during or after the interviews nor was referred to any counselling service.

3.3.6.2 Participant's autonomy and informed consent

Informed consent involved the process by which research participants voluntarily confirmed their willingness (in writing) to participate in the research after they had been provided with necessary information regarding the research and what their participation would entail. This was done using the participant information sheet (see section 3.3.4.4). To ensure each participant's autonomy, he/she was informed that participation was completely voluntary and they could withdraw at any time during the interview if they wish without giving any reasons. Participants had the option of returning their signed consent form to the researcher either by post or email. Participants recruited through the NHS returned their signed consent forms to the gate-keeping HCPs who subsequently forwarded them to the researcher. Participants had the opportunity to seek clarifications or ask further questions from the researcher or HCPs prior to confirming their decision to participate in the study. Further information on how many

participants consented to participate, how many declined to participate and reasons for non-participation are also discussed in **Paper 2**.

3.3.6.3 Confidentiality

Only required personal data were collected in line with the Data Protection Act 1998 and the General Data Protection Regulation (2018). To further ensure compliance with data protection regulations, participants were also informed on their information sheet about how their data would be used and stored. A mobile number specifically set up for the study and the researcher's university email address were used to make contact with interested participants. Collected data were securely stored on password-protected computers and locked cabinets with access restricted only to the researcher and her supervisors. For additional protection of data, the researcher used a computer with approved encryption software for data analysis. Data including interview recordings are being securely kept for ten years after which they will be destroyed in line with the University Policy for the Governance of Research Involving Human Participants (Ulster University 2015). No identifiable data was used in the data analysis and real names were replaced with pseudonyms. Pseudonyms were preferred to identification numbers in order to ensure participants were personified as subjects without compromising on their anonymity. Where a telephone or Skype interview was preferred, the researcher ensured this was done in a separate room allocated for such purpose at the University. Participants were also advised to use a private area at their end to ensure their privacy.

3.3.6.4 *Non-maleficence (Do no harm)*

To ensure participants' safety and welfare (physical/mental), interviews were conducted at their preferred time and venue/mode. Where face-to-face interviews were preferred, the researcher travelled to meet with participants at their choice location as this helped to avoid any financial or travel burden being placed on them. The researcher's safety was addressed by ensuring that her supervisors had the schedule of interview venues and times. She also maintained regular contact with her lead supervisor throughout the data collection process explaining her movement before and after the interviews. The University's Lone Worker Policy (Ulster University 2016) was also duly observed whilst appropriate insurance cover was provided for the researcher prior to travel for data collection purposes. Participants were informed that participation or non-participation would not affect their healthcare or legal rights as the study was being conducted independently and for academic purposes.

3.3.7 *Data analysis*

Data were analysed using the constant comparison method as it aligned with CGT and also facilitated a clear understanding of the research phenomenon thus enhancing the 'grounding' of the emerging theory in participants' data (Charmaz 2014). Constant comparison is a core element of grounded theory research and it has been widely acknowledged as a useful analytic method which advances reflective thinking (Giles *et al.* 2013; Charmaz 2014; Ramalho *et al.* 2015). Constant comparison involves an iterative comparison of codes, emergent categories and reflective memos with further data until theoretical saturation is achieved (Strauss and Corbin 2008; Charmaz 2014). Following Charmaz's (2014) prescription, data analysis began with the transcripts of the first five interviews (three men, two partners), identifying initial concepts

which were then explored more in subsequent interviews (Creswell 2007). Charmaz's steps were followed when analysing the data and involved initial, focused and theoretical coding techniques. Prior to these, the interview transcripts were uploaded into the NVivo 11 software which was used with other Microsoft packages (Word, Excel and PowerPoint) to manage the data analysis process as explained next.

3.3.7.1 Computer-Assisted Qualitative Data Analysis

The usefulness of software in helping to organise large amounts of unstructured interview data into manageable codes for more efficient analysis is well reported in the literature (NVivo 2018). This is known as computer-assisted qualitative data analysis (CAQDAS) and NVivo 11 software has gained increasing prominence over the years (NVivo 2018). NVivo 11 helped to facilitate quicker coding and creation of large amounts of codes from the interview transcripts, which were more easily grouped into themes as appropriate. Although learning how to use the software efficiently can be time-consuming and very reliant on the researcher's qualitative and creative skills (as the researcher has to also develop the codes), the researcher's prior experience of using the software, attendance at refresher training courses and constant practice were helpful in dealing with these challenges. Transcription of the 38 interview recordings was completed by the researcher using Microsoft Word after which the transcripts were uploaded into the NVivo software. Time constraints informed the use of professional transcribers for the two focus group recordings. However, the researcher ensured to listen to the recordings and double checked with the transcripts to ensure validity. Necessary corrections were made by the researcher before the transcripts were uploaded into NVivo for analysis. NVivo was helpful in managing the large amount of data generated in the interviews especially during the initial coding process where lots

of initial codes were generated. However, conducting manual analysis (writing theme/category ideas on note books, word documents, flip charts) (Appendix 12) was more useful during the focused and theoretical coding processes as this facilitated a more rigorous data analysis through open discussion and validation of ideas with supervisors. Although the data analysis process was more iterative than linear, the key stages involved are summarised in figure 2. Each of these stages are now discussed.

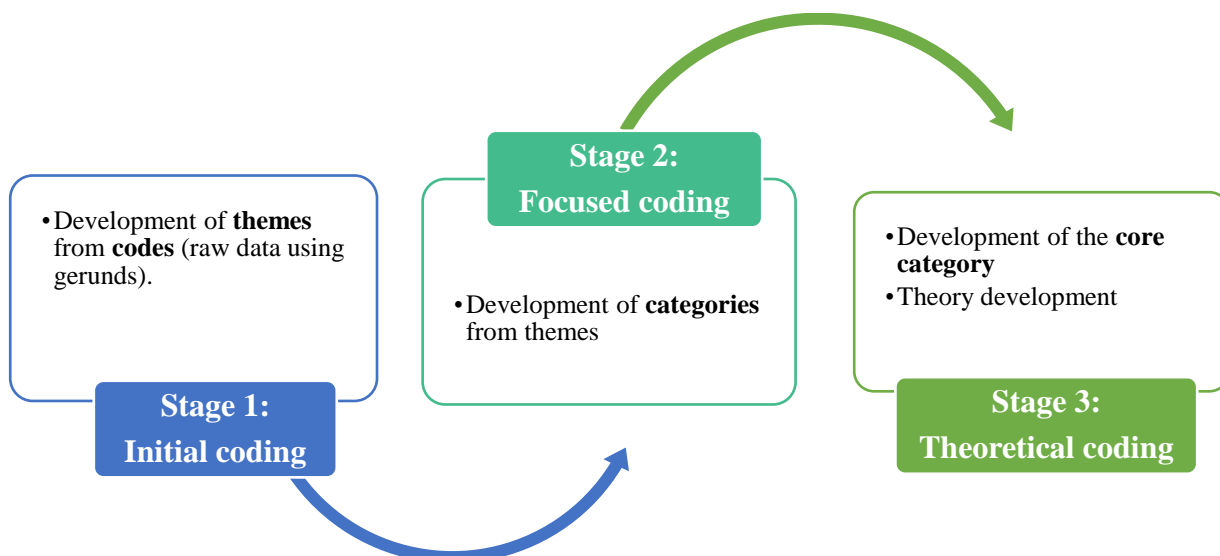


Figure 2: Stages Involved in Data Analysis

3.3.7.2 Initial coding

This first stage involved the development of codes from the data to form themes. Following verbatim transcription of the first five interviews (men=3, partners=2) and reading of the data, codes were developed by marking similar words or phrases using gerunds (action words and processes) in participants' narratives. Where they were perceived to convey the meaning better and to keep close to the data as much as possible, participants' own words were used in the initial coding process. Initial coding enabled the researcher to have an overview of what was

happening in the data. Gaps in the data which required further exploration in future interviews were also identified at this stage (Charmaz 2014). Within the large number of codes developed at this stage, those which described similar ideas were grouped into themes. For example, in the men's data, there were narratives around disclosure with one man stating he was secretive about it and also instructed his wife not to disclose. This was initially coded as 'protecting disclosure'. The other two men also talked about disclosure but highlighted they were more open about it. This was coded as 'readily disclosing'. As these ideas were still about disclosure of the CaP illness although with varying perspectives, the codes were combined into a theme and relabelled as 'managing disclosure' as this captured both sides of the story better. Other ideas within the data which were related to disclosure were also included in this theme. The same process was used for the rest of the data and also for partner data at this stage.

Decisions regarding which themes were important for further exploration were guided by the most prevalent themes within the data and also following in-depth discussions with the researcher's supervisors. Keeping focus on the research aims and objectives also helped to identify relevant themes from the large mass of data gathered initially. For example, the theme 'managing disclosure' was prevalent within the data and seemed to be impacting on the men's support experiences and that of their partners all through the CaP journey. This theme, although emerged spontaneously from research participants themselves (both men and partners), was very relevant to addressing the research aim. Hence, it was considered important to follow this lead in later interviews to investigate reasons for men's decision to disclose or not. The implications of disclosure on both men's and partners' support experiences were also investigated further in their respective interviews. Further examples on how emerging themes directed subsequent

interviews is provided in the reflective memo (Appendix 13) and can be seen in the modification of the topic guides.

3.3.7.3 Focused coding

This involved a more conceptual level of coding to explore relationships between themes and compare them with new data to form categories. Participants' psychological inclinations (why), responses (what) and social processes (patterns of behaviour) were probed within the data in line with the study's aims and objectives (Charmaz 2014). Related themes were then grouped into categories which were explored in greater detail in further interviews. For example, all themes which captured men's description of ownership and control of their illness (for instance, the example used earlier, 'managing disclosure') were seen to be central within their data, thus 'owning the illness' became the resulting category and was triangulated across partners' and HCPs' data for similarities and variations. Partners' data showed a similar trend of the men's ownership behaviour as there were themes (for example, 'the unrecognised co-patient of CaP') which described the partners being in a background role (for example, in decision making regarding disclosure, access to support). The themes were thus grouped into one category and labelled as 'Partner in the passenger seat'. Emerging themes from HCPs' data (for example, 'exclusion of partners') also showed that BA/BC men were often at the forefront of their illness with minimal inclusion of partners both in the men's decision-making and accessing of healthcare support. Such themes from the HCPs' data were categorised as 'HCPs recognising the difference' as they had noted this behaviour of BA/BC with CaP was different from that of Caucasian men.

3.3.7.4 Theoretical coding

The final stage of the analysis was theoretical coding which was more analytical than the two previous stages and culminated in the identification of the core category. As data analysis progressed, categories which emerged from each of the three data sets (men, partners and HCPs) were iteratively compared with each other and also explored with additional data (theoretical sampling) for similarities and variations. Related categories from the three data sets were subsequently aggregated to develop the core category ‘man in the driving seat’ which embodied the central idea within the data and succinctly captured the main themes within the varied perspectives of the men, partners and HCPs. The core category was constantly compared with more data until completely refined and saturated (Charmaz 2014; Foley and Timonen 2015). Saturation was deliberated with supervisors and was agreed to have been achieved when the patterns of behaviour and the implications these had on the men’s and partners’ experiences along the CaP journey were well understood and conceptualised.

3.3.7.5 Theory development

As mentioned earlier (Chapter Two, section 2.5), formal theories are often underpinned by objectivism and aimed at generalisations (Sutphin *et al.* 2013) whilst substantive theories are usually underpinned by interpretivism and explain a particular idea in greater depth within a given context (Glaser and Strauss 2017). One of the aims of this research was to seek an in-depth understanding of the experiences of BA and BC men treated for CaP and their partners within their specific attributional (BA/BC cultural setting) and relational (UK) contexts. This aim, coupled with the qualitative paradigm and social constructivist perspective which underpinned

the conduct of this study, informed the decision to develop a substantive theory instead of a formal theory (Glaser and Strauss 2017).

In developing the substantive theory, the elements of theorising as described by Charmaz (2014, pg.244) were followed: '*stopping, pondering and thinking afresh*'. '*Stopping*' and '*pondering*' were achieved by pacing the collection in order to take time to analyse and reflect on the emerging categories and identify gap areas requiring further in-depth exploration. To facilitate '*thinking afresh*', the emerging theory was co-constructed with supervisors through expert validation and building of ideas with other researchers. This involved in-depth and iterative group discussions on the categories (in relation to the data) and documenting ideas on note books, word documents and flipcharts. The discussions also helped to address differences in interpretation of the data until a consensus was reached. Theoretical sampling also facilitated data triangulation among participants and provided them with an opportunity to contribute to the development of the theory. Theoretical sensitivity^g, which has been highlighted as an important element in the theory development process was achieved in this study by following Charmaz's (2014) recommended steps (Table 3).

Table 3: Steps Taken to Enhance Theoretical Sensitivity

a)	The research phenomenon was explored from multiple perspectives involving different sample groups of participants (men, partners, HCPs) and supervisors (in data analysis).
b)	Data were analysed using constant comparison which involved a comparison of data with data, data with codes, codes with codes and codes with categories until theoretical saturation was achieved.
c)	Leads were followed by using emerging themes from analysis of initial data to inform the questions asked at the subsequent interviews and also by following direct prompts and leads whilst interviewing (theoretical sampling).
d)	Building on ideas which emanated from analysing the data and researcher's interactions with supervisors, colleagues, the literature and other non-academic sources (for example, daily interactions with lay people).

The substantive theory integrated the core category and related categories which reflected similar ideas from the three data sets and conceptually explained the experiences of BA/BC men and their partners along the CaP journey (Glaser and Holton 2005). Only categories with related properties to the core category were included to form the substantive theory. For example, from the men's data, the two categories which described the men's pattern of behaviour (basic social processes) and had similar properties to the core category were: 'owning the illness' and 'navigating the journey through a bumpy terrain', hence these were included in the theory. From the partners' data, 'partner in the passenger seat' was the relevant category while 'HCPs recognising the difference' was the relevant category from the HCPs' data. These two categories were also included to complete the theory.

The final theory was made up of one core category and four related categories abstractly labelled using metaphors in order to make their meanings practical and understandable to lay participants (Glaser and Straus 2017). Deliberations with research supervisors also identified

that the comprehensibility of the substantive theory could be enhanced by using metaphors to illustrate the core category and its associated categories within the context of a journey. Some participants (especially among the men) also used the word ‘journey’ many times within their narratives. For example, the CaP experience was seen as a journey for the men and their partners as they narrated their stories from what led to the diagnosis up until life after treatment. Properties within the three data sets also indicated that within this journey, the men took the leading role in terms of ownership, responsibility and control of key aspects of the CaP experience (for example, getting diagnosed, disclosure and managing post-treatment side effects). This informed the use of the metaphor ‘man in the driving seat’ to label the core category and this was also adopted for the substantive theory. A conceptual model of the theory is presented in Chapter Four, Figure 3. The data analysis process was iteratively done using a rigorous process as outlined above. Specific measures taken to ensure rigour and trustworthiness in this study, are discussed next.

3.4 Rigour and Trustworthiness

Debates exist around the preferred terms to describe rigour and measure quality in qualitative research. Some researchers (for example, Morse *et al.* 2008) assert that the terms reliability and validity which are often affiliated with quantitative research also have applications in qualitative research. Other researchers (for example, Lincoln and Guba 1986; Connelly 2016) argue that such terms do not provide a good fit for qualitative research and should thus be replaced with ‘trustworthiness’. Regardless of these debates, the need to ensure research quality and provide believable evidence suggests that all research must demonstrate rigour irrespective of its research design or the concepts used in describing its quality criteria. The researcher

identifies with Lincoln *et al* (2011) regarding the use of ‘trustworthiness’ as a more ‘qualitative’ term to demonstrate how rigour and quality were ensured in this study. Trustworthiness has been used to describe how credible (true), transferable (applicable), dependable (consistent) and confirmable evidence produced by using qualitative methods are (Lincoln and Guba 1986).

Heath (2006) highlighted the need to avoid the methodological vulnerability of researchers imposing their preconceived assumptions (informed by early literature review) on the research data. To avoid such methodological vulnerability and also address Glaser’s concern of potential ‘data contamination’ with preconceived ideas (see Chapter Two, section 2.2), the researcher having conducted an early literature review, adopted a critical and reflexive approach to the data collection and analysis processes. This helped to mitigate the potential influence of early engagement with the literature (Dunne 2011; Thornberg and Charmaz 2014). Reflexivity was done by: clarifying the researcher’s philosophical assumptions and preconceptions (see section 3.2) before data collection; setting aside her preconceptions (informed by literature) until categories were developed during data analysis (Charmaz 2014; Ramalho *et al.* 2015); and keeping reflective and theoretical memos (Foley and Timonen 2015). Other steps taken to ensure trustworthiness in this study are explained in relation to each of its different components below.

3.4.1 Credibility

To ensure credibility in CGT studies, Charmaz (2014) recommends data triangulation (use of multiple perspectives to validate researcher’s interpretation of the data). In this current study, data triangulation was firstly achieved by exploring emerging concepts further in subsequent interviews and across different sources (theoretical sampling with men, partners and HCPs). This allowed participants to validate or/and elaborate on the researcher’s interpretation of the data

(member checking). Secondly, data was triangulated through peer validation with the researcher's supervisors during the analysis process (Ritchie *et al.* 2013). This helped to deal with the researcher's subjectivity and potential bias (due to shared ethnicity with study participants) in the data analysis process. Thirdly, participants' quotes were used in reporting research findings as this provided 'thick descriptions' necessary to substantiate evidence provided in the study (Houghton *et al.* 2012; Gentles *et al.* 2015). Fourthly, variant cases were also considered and reported to highlight the variations in participants' own perceptions of their experiences without the researcher 'forcing' their data (Charmaz 2014). For example, the varying perspectives of the men participants towards disclosure were considered and reported. Credibility was further enhanced by ensuring methodological congruence in which the researcher's philosophical assumptions and methodology choice aligned with the research aims and objectives (Connelly 2016).

3.4.2 Transferability

Qualitative studies do not aim for generalisation but an in-depth understanding of a given phenomenon (Bryman 2015). However, as an indication of trustworthiness, Lincoln *et al.* (2011) highlight the need for researchers to still demonstrate that their study findings may be transferable to similar contexts. To enable other researchers to determine the potential transferability of findings from this study to similar context, participants' demographic details were collected during the interviews and reported (see Chapter Four, Table 4). To further enhance transferability, it was necessary to clarify the specific context within which participants narrated their experiences (Houghton *et al.* 2012; Gentles *et al.* 2015). This was done by including age and ethnic orientation (for men and partners) or job title (for HCPs) in participants' quotes.

3.4.3 Dependability

Dependability has been defined as a consistency in research results if the study was replicated in similar context using same procedures (Bryman 2015). Evidence highlights the pivotal role of memos in ensuring dependability in grounded theory research (Charmaz 2014; Foley and Timonen 2015). Memos which provide documented details of reflections on the interviews (field notes, see example in Appendix 14), analytical insights into emerging themes (reflective memo, see example in Appendix 13) and researcher's conceptual interpretation of the data to develop a theory (theoretical memo, see example in Appendix 15) were all kept. Keeping reflective and theoretical memos enhanced theoretical sensitivity and provided a transparent documentation of the researcher's thought processes about the data and how links between emerging patterns were articulated. As suggested by Foley and Timonen (2015), an audit trail of key methodological decisions, actions and procedures were also accurately documented in minutes of supervision meetings (see example in Appendix 16) to further enhance dependability in this study.

3.4.4 Confirmability

Confirmability has been used as a concept to explain the integrity of research findings which should be devoid of biases (Lincoln *et al.* 2011). Grounded theory researchers further emphasise the need to ensure that the resulting theory is well grounded in participants' data without the researcher 'forcing' their preconceived ideas or biases (Glaser and Strauss 1967; Charmaz 2014; Strauss and Corbin 2008;). To achieve this, researcher reflexivity has been recommended as this involves that the researcher identifies and clearly states any preconceived ideas, biases, philosophical assumptions, personal interest or professional roles and how these may have

influenced the research process (Lincoln *et al.* 2011; Doyle 2013; Engward and Davis 2015). Hence, prior to field work, the researcher clearly documented her philosophical assumptions (see section 3.2). To further reduce bias and ensure that findings are reflective of participants' data, the researcher made conscious effort to maintain an open mind during the data collection (for example, by using open ended questions) and analysis (for example, co-construction of theory with research participants and supervisors) processes.

3.5 Summary

This chapter described how the PhD study was conducted. CGT was used as informed by: the research aims and objectives; the researcher's social constructivist worldview; and a methodological gap in the literature for a substantive theory to understand an under-studied phenomenon. Eligible participants participated in interviews and focus groups at mutually agreed mode, venue and time. Constant comparison guided data analysis which culminated into the development of a substantive theory. Necessary measures were taken to ensure rigour and trustworthiness of study findings. All necessary ethical considerations were duly observed. Findings from the study are reported in the next chapter.

CHAPTER FOUR: FINDINGS

4.1 Introduction

This chapter is presented in three main sections. The first section presents an overview of the research findings, including participants' demographic details. The second section reports data from each of the three sample groups involved in the study, that is, men, partners (summary) and HCPs. The final section presents the substantive theory which helped to move the data beyond description to analytical conceptualisation. Participants' quotes have been used to support and contextualise findings. Findings from partners have been published (**Paper 3**) is included at the end of section 4.4.

4.2 Overview of findings

A total of twenty five men, eleven partners and eleven HCPs ($n = 47$) participated in thirty eight in-depth interviews and two focus groups (consisting of five and four HCPs respectively). Lasting on average between 30 – 90 minutes, thirty one of the interviews were conducted face-to-face, five via Skype and the remaining two by telephone. The focus groups were held at the HCPs' respective Trust and lasted between 30 – 45mins. Participants' demographic details are provided in Table 4. The average ages for the men and partners were 65 years and 58 years respectively. The HCPs were from different members of the multi-professional team within the uro-oncology department and all had experience of caring for Black men with CaP either at the initial stages leading up to diagnosis and/or after treatment.

Table 4: Participants' Demographics

	Men (n=25)	Partners (n=11)	HCPs (n=11)
Gender			*
Male	25	-	
Female	-	11	
Ethnicity			*
Black Caribbean (BC)			
Jamaica	8	2	
Barbados	4	2	
Guyana	1	-	
Montserrat	1	-	
St. Lucia	1	-	
Caribbean Virgin Islands	1	-	
Dominica	1	-	
Black African (BA)			
Nigeria	2	1	
Ghana	4	2	
Sierra Leone	2	-	
Caucasian			
White British	-	2	
White Irish	-	1	
Spanish	-	1	
Age (years)			*
< 45	-	1	
45 – 55	3	5	
56 – 65	11	2	
66 – 74	6	2	
75 and above	5	1	
Length of time since active treatment for CaP		*	*
>3 months <one year	3		
One to five years	10		
>5 years	10		
Ongoing longer term treatment	2		
Treatment type		*	*
Surgery (including robotic)	8		
Brachytherapy	5		
Radiotherapy + hormone treatment	7		
Surgery + radiotherapy	3		
Hormone treatment + chemotherapy	1		
Hormone treatment + cryotherapy	1		
			*

Marital Status			
Married (in years)			
< 20	7	4	
21-30	3	2	
31-40	3	3	
>40	6	2	
Not specified	1	-	
With unmarried partner	3	-	
Single	1	-	
Widowed	1		
Educational Qualification			*
Below graduate	13	3	
Graduate	5	4	
Post graduate	5	4	
Not specified	2	-	
Employment type			*
Skilled/professional jobs	5	4	
Semi-skilled/unskilled) jobs	5	-	
Self employed	3	2	
Retired	11	4	
Not specified	1	1	
Length of time since resident in the UK			*
< 20years	1	-	
20-30 years	7	5	
>30 years	16	5	
Not specified	1	1	
Job role	*	*	
Consultant Urologist			2
Consultant Oncologist			1
Consultant Radiologist			1
Uro-Oncology Nurses			4
Urology Clinical Nurse			2
Specialist			
Urology Trainee			1

*data not deemed applicable

There were similarities and variations in participants' views and experiences within and across the three sample groups. Regardless of whether the men were BA or BC, they constantly used the word 'Black' as an umbrella term to describe themselves, placing less emphasis on their African or Caribbean descent. Hence the word 'Black' is also adopted in reporting their findings but their specific ethnic affiliation will be mentioned where relevant to enhance a contextual understanding of some of their narratives.

4.3 Experiences and needs of Black African and Black Caribbean men with prostate cancer

Twenty five men participated in the interviews. Analysis of the men's data yielded nine themes which were theoretically coded into four broad categories: 1) Owning the illness; 2) Feeling "less of a man"; 3) Navigating the journey through a bumpy terrain; and 4) Bridging the support gap.

4.3.1 Owning the illness

Findings showed that the men took ownership of their CaP illness from diagnosis, to treatment and post-treatment. The men highlighted that as it was their own bodies affected by CaP, this implied that they had to take ownership of themselves and the decisions related to their illness, minimally involving their partners. Three themes which contributed to this category are: *'starting a journey into the unknown'*; *'retaining control'*; and *'managing disclosure'*.

4.3.1.1 Starting a journey into the unknown – the reality

Many of the men noted that although they had been aware of their risks of developing CaP either due to a family history of the disease or information received from other sources (friends who had been previously diagnosed, media programmes), they were shocked when they themselves were diagnosed. Men's responses to the CaP diagnosis varied. The majority reported they were psychologically distressed as they associated the diagnosis with imminent death, which they dreaded. Some men's psychological distress was further increased by their uncertainties around the implications of being diagnosed, asking themselves questions such as *'why me'?* and *'what next'?* For such men, they were primarily concerned with the potential wider impact their

CaP diagnosis may have on their dependant family's welfare due to their own role as the family's main breadwinner:

"...I was scared erm I'm a very practical man erm and I'm also the breadwinner, so my family is very reliant on me in terms of you know financial well-being...I was scared for them I was saying then how do I make provisions for them, what's the next steps..." (Chris, BC, 51)

Some men reported they were less psychologically affected by the news of their diagnosis as they described feelings of inner peace which they attributed to their religious faith that God will '*get things sorted*' for them. For some men, priority for survival informed their promptness in taking up medical treatment. They were guided by their doctor's recommendations, advice from peers who had undergone a similar experience and by seeking additional information online. In contrast, other men delayed medical treatment because they were trying traditional remedies (for example herbs) first. This was mostly motivated by the men's desire to recover naturally without having to undergo medical procedures which they perceived as an invasion on their bodies. Some men who had also initially delayed treatment for religious reasons noted that they only took up medical treatment after their pastors advised them that medical treatment can be a route to the divine healing the men desired:

"...they did all the test and they tell me that I have got prostate cancer but I reject it, I reject it in Jesus name, and what happened, my pastor said to me and his wife, they said to me 'go and have treatment' because I wasn't gonna have treatment, but they said to me 'go and have the treatment because God can work through these people (doctors)' so I went and ...they started giving me, I was getting the radiotherapy..." (Mr Vincent, BC, 64)

Another man also reported he delayed treatment because his mother died around the time of his diagnosis and he felt obliged to travel to his home country to bury her before returning to take up treatment for his CaP. Irrespective of the treatment type they had (see Table 4), men experienced one or more symptoms of sexual dysfunction, fatigue and/or incontinence issues afterwards. The

men recalled how dealing with the practical life experiences of these treatment side effects was more challenging compared to what they had been told by their doctors or read in the literature.

4.3.1.2 Retaining control

For the majority of the men, a successful CaP treatment helped them overcome the initial psychological distress they had experienced at diagnosis. The men's priority thus shifted from wanting survival to retaining control of their lives amidst the disruptions caused by treatment-related side effects. This was especially in regards to being able to continue to fulfil their manly duties (for example earning money):

“...but I need to earn my money, I mean you are already taking my manliness away, taking everything away from me, you are stripping me bit by bit, right, I just thought no, I have to take charge of my life, and that is what I came to decision, that cost what it will cost, I have to take charge of my life, I have to be looked up to again as a man...” (Mr Nelson, BC, 59)

Men's narratives further showed a desire for them to be independent of medications and clinical aids as they adopted alternative ways of dealing with their post-treatment side effects at their own pace and discretion, minimally involving their partners. For example, some men highlighted that they deliberately refused to use the incontinence pads provided by their healthcare team in order to avoid being dependent on such, as their priority was to return to normality (their pre-treatment way of life) as quickly as possible:

“...and because I've made a decision not to wear any nappies, because I thought that if I wore them there is a dependency that I won't have to think as hard...so there was a mental thing in my head saying that if I relied on those, then my body won't readjust, so you need to push yourself to try and get back to normality...” (Mr Ben, BA, 50)

Men who ardently engaged in physical activity routines prior to their CaP diagnosis also added that a desire to retain their pre-treatment lifestyle motivated them to continue to exercise regardless of treatment-related fatigue.

4.3.1.3 Managing disclosure

Findings showed that only a few of the men publicly disclosed their CaP illness, whilst the majority of them kept it as a private affair and made deliberate choices regarding who to tell and why. Many of the men contained disclosure to their healthcare team, wives/partners and employers. Men described how they restricted their wives from disclosing the CaP to their wider social network. Some men believed that public disclosure of their CaP could make them appear weak and be perceived as admitting vulnerability, which they noted was not consistent with their personal identity:

“...and no, I didn’t tell, because wife goes to church pretty much every Sunday and I said to her, do not tell people at church that I got any illness... because I won’t be wrapped in cotton wool, no no, it’s not me, it’s not me to get oh poor you... I don’t feel comfortable...”
(Mr Fred, BC, 62)

There were also perceptions that disclosure of the CaP within their wider social network could prompt fear which some men identified as being related to their beliefs around cancer fatality. This informed some men’s decision to avoid disclosing their diagnosis to their children in order not to frighten them into thinking their dad was dying. These men gave their children alternative reasons (for example, back operation) to explain frequent visits to the hospital. Some men added that restricting wider disclosure of their CaP enabled them to retain control over their personal information and avoid potential manipulation by witchcraft. The men highlighted that public disclosure could risk their illness information getting to people who could use witchcraft to manipulate the sickness out of their control to harm them. This notion was more common among the BA participants. Reiterating a desire to retain control over their personal information, others added that limited disclosure was necessary for them to avoid social stigma related to a cancer diagnosis:

“...I strongly believe that the less people know about what is happening in your life, the less you need to need to, because if nobody knows anything, nobody’s going to discuss about it....it’s a stigma, because when you’ve got cancer, then they start counting your days for you, and I think you know I’ll feel angry and furious if someone comes and say ‘this guy has got cancer, he’s going to die soon’ that sort of thing, so if they don’t know anything, they will not say anything...” (Mr Dave, BA, 62)

Men explained this reticence to share as stemming from perceptions of a CaP diagnosis as a taboo subject often avoided due to the implications it has for men’s reproductive ability which crucially defines their masculine identity. The men regarded this as an important but private matter. The embarrassment of going through the initial diagnostic procedure (rectal examination) made it difficult for men to talk about CaP as the procedure itself could prompt stigmatisation for them:

“...as a Black man, sex is quite high on the priority list...but Black men I think sexually tend to be quite private erm we struggle to even have discussion with our peers about prostate cancer, ...it’s a stigma sort of thing you know, and ...as a Black person you sort of feel embarrassed to even have the initial examination, ...” (Mr Kelvin, BC, 56)

Other men were more receptive towards public disclosure of their CaP as they highlighted this helped them to deal with the challenges of living with the disease. For example, some men noted sharing their CaP among their wider social network allowed them to be aware of additional useful information (for example, supplementary therapies) which helped them cope with treatment-related fatigue and pain. Others stated that reflecting on their CaP experience inspired them to serve as peer champion for other men (including their older male children) to sensitise others of their potential risk of developing the disease and encourage them to get checked and treated promptly (if diagnosed). The men admitted that talking about their illness this way was gratifying for them especially whenever they saw men taking action in response to their talks. Some men highlighted that sharing their experience with their male children could help prepare them for how to deal with CaP diagnosis if occurred to them in the future:

“...I have three boys and I thought it’s a good thing to tell them ... so we found some time and had a chat with them about it...that from 40 everyone must check their PSA regularly to make sure that they are fine, if they are not, it’s not the end of the world because if it’s discovered early they will be fine and I think once we have that kind of relationship and they know whether I’ve been through it and how I’m handling it, It will help them also to deal with any situation they may find themselves in, ...”(Mr Okri, BA, 58)

Some men also narrated that publicly talking about their CaP illness helped them to overcome their own fear of cancer fatality.

4.3.2 Feeling “less of a man”

The majority of the men articulated their masculine identity and role were challenged due to the physical changes resulting from treatment side effects. Two themes contributed to this category: ‘*losing sex life as known*’; and ‘*experiencing threat to identity and role as a man and family breadwinner*’.

4.3.2.1 Losing sex life as known

Generally, there was substantial decline in men’s ability to spontaneously engage in sexual intercourse with their partners, which many of them acknowledged had the most significant impact on their perceptions of being a complete man. Some men who had hormone treatment experienced a complete loss of libido which they recounted made them feel “*less of a man*” especially whenever they reminisced on how sexually active and potent they were prior to having treatment for CaP. Although the men acknowledged that their wives had been supportive and understanding, this did not relieve their feelings of sadness for losing their libido:

“...less of a man, without a doubt, less of a man because as far as I was concerned, I was a man, in that where I was in my life...you are now realising the medication is doing all this thing (loss of libido)... you think to yourself, is that how I am going to be for the rest of my days, because it ain’t good, it just ain’t good, and we (himself and wife) will just sit here having a chat, watching tv, that happens but anything else (sexual intimacy), (shrugs) and

you just say to yourself it's the medication but you know they (doctors) make it clear, if you don't take it, death, and you think, fine but what sort of life am I living...?" (Mr Nelson, BC, 59)

Men who had other treatment procedures (for example surgery or brachytherapy) also narrated that they experienced one or more of erectile problems (for example, lack or weak erections), painful sex, dry/retrograde ejaculations^g and weak orgasms. Inability to engage in penetrative sex due to erectile dysfunction was perceived as frustrating for men as they felt they were still in the young (below 60 years) phase of their lives where sex was an important part of their relationship. Although some men noted they were now in remission from the CaP, their post-treatment sexual dysfunction was a depressing reminder of the debilitating impact of the disease. Regardless of their age, men's psychological concerns over the decline in their sexual function were mostly underpinned by their cultural perceptions of sex as an important determinant of their masculine identity as a complete man. The men explained these in terms of their ability to have children if and when they wanted (virility) and also being able to provide sexual satisfaction for their partner:

"...again I think it comes to masculinity, machoism... being a man, being able to perform, being able to satisfy your wife, that is the Black person's perception of masculinity yes I can perform, my wife feels good ...that is..." (Mr Ron, BA, 56)

Some men added that even though they could engage in some penetrative sex with their partners, experiences of dry ejaculation made the activity less satisfying for them (men) as this reminded them of their loss of reproductive ability. Such men resigned to fate encouraging themselves that *'at least they were alive'*.

4.3.2.2. *Experiencing threat to identity and role as a man and family breadwinner*

Findings showed that treatment-related fatigue significantly challenged some men's role as the main family breadwinner, mostly because of the impact this had on their work lives. For

example, some men (especially those who had hormone treatment with radiotherapy or chemotherapy) reported they found it difficult to return to work due to severe fatigue and had to retire much earlier than they would have liked:

“...after twelve weeks or something like that, the bus company called me and said they can’t keep paying me because I have been sick for too long so they will give me early retirement, so I took the early retirement...” (Mr Vincent, BC, 64)

Some men described this as a difficult period for them because of the impact on their financial lives. Although the men were grateful to have access to free healthcare, their limited ability to meet up with their financial obligations as the family breadwinner was very upsetting for some and challenged their personal perceptions of being an ideal man. Some men had partners who were working and supported the family financially during the time the men were off work, nonetheless, resuming their role as the family breadwinner remained an important priority for the men. For example, one man described his inability to return to work quickly as ‘*killing*’ as he was still in his productive age where ‘*earning his money*’ was very important to him. The man recounted that he prioritised his breadwinning role over the potential risk of dying from the CaP if he missed out any of his treatment appointments:

“...and the oncologist spoke to me and said ‘if you come off this (treatment) you will die’, and my words to him was if I don’t, I will die, you need to understand my mental state right now and he acknowledged that ...and I said well let’s put it this way, if you do not work something out for me, I am coming off, there is nothing you can do for me or anybody can do I am coming off, I know the consequences but if I don’t, I’m gonna die so you have to understand where I am at, I need to earn my money I need to be there for my family I need to be able to provide for my family and as I tried to explain you know you are in two spectrums, one spectrum is that I have to as a man look after my family, I have to, the second is that if I don’t, if I am not able to turn around and have that ability to provide for myself then mentally it is destroying me, it will destroy me, so there were those kind of thoughts that I was having...” (Mr Nelson, BC, 59)

For men treated with surgery (especially the younger men aged less than 60 years), they experienced less fatigue and were grateful to be able to return to work quickly as they felt less

pressured to meet the perceived financial obligations for themselves and their dependant family. Men added that having made substantial investments (for example, investing into properties) prior to their diagnosis and also having a wife and children who were financially independent, enhanced their ability to cope financially during their illness:

“...I was not really affected financially because when I was younger I had made provision for retirement so that you can still live a decent life when you retire as when you were working, so I could still live a life now as when I was working, I had invested in properties...and my wife she is ok too, so it has not really affected financially, medically anyone suffering from cancer they get free prescription, I have insurance for many medical things...” (Mr Mike, BC, 68)

Treatment-related incontinence further posed as a threat to some men's self-esteem. They reported being adversely impacted by stress incontinence, painful urinations, haematuria^g, which necessitated them to make significant adjustments to their social lives. Some men described life after treatment as ‘*the battle*’ as they narrated that their inability to control their bladder post-treatment was humiliating and negatively impacted on their personal self-esteem:

“...so eventually I had the surgery done on a weekend, and then erm on Monday morning I was discharged home, but then that was when the battle started, you know...you must have read about prostate cancer, you know, that erm, one of the immediate side effects was incontinence, you know, which was er very very humiliating, very very humiliating, you feel dirty, you know, I mean... (sarcastic laugh), it takes away your confidence, your dignity, your everything...” (Mr Ellis, BA, 74)

Men were also bothered by unwanted weight gain associated with their hormone treatment as this restricted their ability to exercise and regain their pre-treatment body shape. Such men emphasised that their body image was important to them as it depicted physical fitness which they had always exercised to maintain prior to their CaP treatment.

4.3.3 Navigating the journey through a bumpy terrain

Amidst their post-treatment challenges, men devised personal coping strategies which were supplemented with the external support they received from different sources along the way. Three themes contributed to this category: *‘coping with loss of sex life as known’*; *‘stepping up to the new norm’*; and *‘accessing support’*.

4.3.3.1 Coping with loss of sex life as known

Findings showed that the reality of losing their spontaneous sexual arousal and/or function to CaP had an impact on the majority of the men after treatment, which they described as disappointing for them. In particular, some men felt discouraged that they now have to ‘prepare’ for sex by using clinical aids which they noted were sometimes not effective enough to help them achieve erections. The men were unhappy about this and reported they now viewed sex as a marital obligation which they have to meet as a husband, rather than a pleasurable activity they used to enjoy with their partner prior to CaP treatment:

“...I mean this thing has really hit me in the sense that there are times when I am just lying down I think about previously oh we could just get on with it but now I can’t, and even the fact that I have to go and inject myself before I have sex, that is my headache, that’s my headache and sometimes injecting yourself and it is not firm enough to have sex makes it even worse, ok I am not bothered I won’t do it, but I have to remember that I am not single I am in a relationship and sex is a big part of any relationship, so if I am being selfish with it and didn’t think about the impact on my wife, I’m not being honest with myself and it is not nice, so whether I like it or not I just have to...” (Mr Ron, BA, 56)

Men attempted to navigate the loss of their spontaneous sex lives by boycotting clinical aids and exploring alternative ways to achieve erections (for example, asking partner to give them a ‘blow job’). This appeared to have provided some sexual pleasure but not erection. However, men felt that this was preferable to medicines or clinical devices (as they were taking the lead). Some other men narrated that taking solace in having had children prior to their CaP helped to alleviate the

threat of the disease to their cultural identity as virile men. Others who experienced painful ejaculation related they continued to endure sex until their symptoms abated. Reiterating this, some men viewed their sexual dysfunction as minor in relation to escaping death from CaP:

“... it (erectile dysfunction) doesn't bother me because, I'm happy I'm alive, you know ... I was sick, and I could have died from it and it's a small price to pay when you look at the big picture, in my view, so...” (Mr Fred, BC, 62)

Findings further showed there were communication challenges among couples in discussing the men's sexual problems and its impact on intimate marital relationships. Despite being in a long term marriage (over ten years) with their wife who also expressed a need to discuss the sexual issues, some men admitted they avoided the subject because they (men) did not know what to say. Explaining the barriers to having these conversations, men articulated that discussing their sexual concerns with wives/partners may be perceived as a sign of weakness which is not consistent with the cultural expectations for them (men) to be stoic:

“... I think it's more cultural and the way families are set up because the men always want to feel like they are macho, as men they can't show any sign of weakness or pain in front of their wives and in this particular case, it's painful mentally and everything when you think that you can't have sex when you want to have it...” (Mr Okri, BA, 58)

In contrast, other men reported that having open conversations with their wives helped to promote mutual understanding and increased emotional bonding between them thereby helping them to deal with the loss of sexual activity. Such men attributed this to the intimacy they had developed as a couple prior to the CaP diagnosis. Regardless of their differing attitudes towards marital communications on sexual problems, nearly all the men identified sexual recovery as their priority need. They identified the need for tailored professional support to guide and empower them to self-manage their sexual problems without appearing emotionally weak.

4.3.3.2 Stepping up to the new norm

Living with post-treatment challenges became a new norm for men in that many of them showed resilience or positivity (as some men described it) as a coping strategy. Faith and spirituality further enhanced coping as some men commented that their personal prayers, daily confessions of the scriptures and listening to gospel music provided them with the inner strength required to deal with their psychological worries regarding cancer fatality and the daily challenges of living with CaP:

“...and as we speak I got this affirmation that I do every morning, it’s called God’s medicine which renews your faith, confession of the scriptures and erm those things are the ones that keep me going and at times when I am alone I just play gospel music ...otherwise when you are alone you think ...I was always listening to gospel music, and the prayers...” (Mr Ron, BA, 56)

Some men added that religious fasting helped to make adjustments to their lifestyle through healthy eating (choice of food and when to eat it) and weight loss, thereby ‘starving the cancer cells’. Men also used different activities to distract their minds from the physical and psychological challenges of the CaP treatment side effects. For example, humour through comedy programmes provided psychological relief for some men through laughter whilst keeping a daily journal (which was later written up as a book and published) provided an avenue for one man to deal with his concerns through writing. Some men in full time employment returned to work quickly in order to avoid being depressed by their post-treatment challenges:

“...I find it better by going into work, I could sit down here but then I would think about it more if I was sitting here, but because I was at work interacting all day, other work mates come around and sometimes they will be chatting about football and er yea, I find it easier to go to work and you know meet people because you didn’t have that time to think about it once you get busy, I was happy to go to work...” (Mr Larry, BC, 57)

Men coped with the impact of incontinence on their social lives by adjusting their daily activities to accommodate frequent visits to the toilet, ensuring they had access to a bathroom whenever

required and in some cases, having an extra bottle in the car in case of emergencies. One man also reported that smoking helped him to cope with his fear of cancer re-occurrence and fatality.

4.3.3.3 Accessing support

Findings showed that men did receive support for themselves from their partners/immediate family, healthcare team, employers and in a few cases, peers and church pastors. Nearly all the men had partners and highlighted that they were encouraged by their partners' companionship and commitment to stay with them through a challenging experience. Some men added that the shock from the unexpected news of the CaP diagnosis made them blank out of what the doctor was saying but having their partner with them to take notes helped them to retrieve lost information afterwards. For some men, their partners assisted them with an online search for additional information to help guide their decision-making whilst those whose partners had medical knowledge also helped to explain the CaP diagnosis to the men in simple language for them to understand:

“...erm my wife, massive massive support, my wife has been with me, she was the one that did the research and broke it down to me, this is what it is...because up until that moment of the operation, I still couldn't register how serious the problem was, she had to break it down through her medical background, she broke it down and explained it to me in lay man's terms...” (Mr Harry, BC, 60)

A few men who were either single or widowed stated that their children were always there to support them through regular visits and phone calls.

Variations existed in men's perceptions of the support received from their healthcare team. Overall, there were more positive comments than negative. Positive perceptions of healthcare support included being given treatment options (verbally and through information leaflets) which provided some reassurance for the men that the CaP was treatable and helped to allay some of their

initial fears of cancer fatality. Some men added that they appreciated having a professional and empathetic doctor with whom they could discuss their concerns and get helpful advice whenever needed:

“...you know nobody, wants to be sick but when you get sick, you want to be treated with dignity and professionally, and that’s completely what I got with Dr..., if you had a question, a private question say I had this.... what do you reckon, and he will talk to you about it...in a professional fashion, when I got treated by Dr ..., it was perfect, as good as one could expect...” (Mr Fred, BC, 62)

Negative experiences of healthcare were mostly attributed to the diagnosis not being picked up by doctors earlier and having unmet information needs to deal with post-treatment sexual issues. A few men expressed dissatisfaction about what they perceived as lack of sensitivity from their healthcare team. For example, one man recounted that he felt insulted by what he viewed as dismissive behaviour from a HCP and insisted on not wanting to be seen by her anymore for the rest of his healthcare. He explained the HCP was not patient to listen him when he called to discuss his concerns about his urine challenges over the phone. Another man added that he perceived the consultant delegating a nurse to break the news of the CaP diagnosis to him as insensitive as he viewed the consultant as the expert and would have preferred he explained the diagnosis to him directly. The man noted he would have felt more confident to ask the consultant questions directly. Another man narrated that his doctor (who was from another cultural background) had used language which himself (the man) and his partner considered as disrespectful and insensitive. Although he noted the hospital acknowledged that insensitive language was used and apologised, the man insisted on having his care transferred:

“...initially I was having my treatment at ...hospital, then an issue occurred between myself and one of the doctors ... I felt he was disrespecting my wife and looking at him and looking at his culture, I knew where he was coming from and I just thought no I am not having that ..the reports that were written by this doctor, this doctor’s English wasn’t the best English possible and when you look at the terminologies he used, I got to tell you it was awful, it really was awful,... we put an official complaint in, they investigated, came in and

apologised, they said 'yes they were insensitive words used erm and they apologised for that' ... I said transfer me...' (Mr Nelson, BC, 59)

Men who were working received support from their employers (where they shared their diagnosis) and they were also allowed to take as much time as needed. For some men, having a friend who had already experienced CaP served as a source of helpful practical support:

"...you see for me X was a life-saver, because X was already two to three months ahead of me, I was able to use his journey to sort of type mine, ...he sent me lots of literature, URL links and so on... he's been there so he knows it and not been blind...having some help to guide me on my decisions, that kind of balanced me out on my journey, if not for X, it would have been a lot more scary because I would have gone down to a lot more uncharted territory where I couldn't have much better understanding ... so it helped me sort of balanced it out and I was a bit more reassured because of that great help..." (Mr Chris, BC, 51)

A few men disclosed their CaP diagnosis with their church and for those that did, they received support in forms of prayers and encouragement from their pastors and close church friends.

4.3.4 Bridging the support gap

Narratives from the men identified some gaps in their current support experiences for which they offered suggestions to help the service. Men highlighted the need to raise awareness of the high occurrence of CaP among younger BA/BC men and reflect this in informational materials. For example, a BC man who was diagnosed at the age of 39 years narrated how the majority of the information he was provided with had graphics of older men, which distressed him as he thought he was affected by an old man's illness:

"...all the information on prostate cancer presented 60-80 years old men. There were no younger men. This really distressed me as I kept on thinking this was an old man's illness. Nothing that they sent to me related to me. I was 39 not 80 so of course many things an 80-year-old would not do, I was still doing. It was depressing in that sense..." (Mr Will, BC, 51)

There was further suggestion on the need to use culturally sensitive channels (for example, Black HCPs, younger Black men) that they (men) could culturally identify with to disseminate such

information. For example, some men explained they experienced better rapport when they were seen by a Black health professional due to their shared ethnicity which men perceived enabled the doctors to understand their experiences and needs better:

“...it’s very good, you know, I like the rapport that we have, my...doctor is actually Black, so we get on, he is from the Caribbean, we get on, we talk, he understands where I am coming from because it is a Black man to a Black man, you understand what I am saying and with that I feel that I can open up more because I can see that he understands me...” (Mr Nelson, BC, 59)

Men identified that building rapport with their HCPs could facilitate the opportunity for them to have comprehensive discussions essential to identify and address their specific post-treatment needs. Some men thought that this could be achieved by improving on current consultation time and processes which they described was like a ‘conveyor belt’ experience for them. There were further suggestions that having the same HCP(s) who was/were already familiar with their diagnosis and care plan along their continuum of care, could help increase rapport and ensure a seamless follow-up especially after treatment which is the most challenging phase of the CaP journey.

Many of the men highlighted the need for professional sexual counselling services to educate couples early on in the post-treatment phase, about the processes involved in the man’s sexual recovery. For example, one man recalled how his wife had thought that the lack of improvement of his erectile dysfunction was because he was not administering the injection he was given properly. Even though he explained to her that he had followed the right procedure, his explanations did not address his wife’s doubts, until he asked his doctor to speak to reassure her that the persistent lack of erection was not due improper administration of the injection:

“...there was one time when I went to the...hospital and I was telling them about the pump and injection that it was not working ..., because I told them to explain to my wife so they did a speaker phone interview they spoke to her because what she was concerned about was that I wasn’t doing it wrongly in terms of the injection ...so it wasn’t as if I was doing

something wrong because that is what I wanted to be reassured about because she thought I wasn't doing it right you see ...” (Mr Ron, BA, 56)

A few other men opposed the idea of counselling services which they attributed to their personal egoistic reasons and negative stereotypes within their community in which going for counselling could be perceived as an indication of severe mental illness such as ‘madness’ which may attract social stigma:

“...the problem is this as a Black man we are not so into it (counselling), we turn around and say, he thinks I am mad, you get what I am saying, that's how we look at it...” (Mr Nelson, BC, 59)

With regards to how support should be delivered, the majority of the men expressed preference for face-to-face delivery which they perceived as indicative of sensitivity and empathy in healthcare delivery. The men clarified that whilst online resources may be helpful for information to guide their decision-making, it is a less preferable option to deliver sexual support due to lack of human contact. Some men added that online support would be challenging for them to use because they are not confident with the use of computers. Others stated they would be willing to use online support if: the resource was appropriately tailored (for example using images and context they could relate to culturally) to help with their sexual recovery, delivered in a controlled manner, and managed by a qualified professional in order to ensure its credibility.

Other interventions suggested were the use of support groups where men could socialise and share their experiences with and among each other. This was not a mutually shared idea as some men preferred a one-to-one buddy strategy due to their reluctant attitude towards public disclosure of their CaP. Men who supported the idea of having support groups elaborated on how these could provide an avenue for them to broaden their support network and also facilitate increased discussion about the much avoided CaP topic:

“...a lot of men there we would talk about things that would affect us you know, so you get the experience of other people and other people have similar situation as you have you know ...it’s good because you can talk to other people what their experiences are and find out the effects or side effects it is having on them, you know because you might think I am the only one going through that, no it’s not, there are other people feeling the same way, so you know it is helpful...” (Mr Mike, BC, 68)

Relating to each other’s experiences through group discussions was also highlighted as potentially useful to help reduce perceptions of stigma associated with CaP among Black men. In particular, some men suggested the need for Black-focused prostate cancer support groups located at different accessible locations across the UK, where they could feel comfortable to discuss among peers with shared cultural values and perspectives. Reinforcing this idea, a few men added that a directory of Black-focused prostate cancer support groups should be compiled so that HCPs could signpost men to them as part of routine follow up practice. There were also suggestions that having annual social events which bring all survivors together could be psychologically refreshing for the men as this could provide an avenue for the men to engage with each other and celebrate their surviving the CaP illness:

“...listen there is a lot of black community network and they are doing great things ...what needs to be done now is it needs to be publicised, right, because these great places are just a step away from you and you don’t even know... set up some kind of directory...let’s get the information ...and then maybe once a year bring everybody together, let us have something like a big event to mark the reasons why we are marking this big event...that is what we need to do...” (Mr Harry, BC, 60)

Men seemed unaware of how their partners might have been impacted by the CaP experience or what the women’s specific support needs were. For most of the men, they felt their partners were strong women who were managing their emotions well and primarily concerned about the men’s welfare:

“...er, she does not have any needs...” (Mr Dave, BA, 62)

However, a few men identified the need to include partners in the CaP care plan stating that this could potentially facilitate improved marital communications between couples. Explaining this further, men highlighted that it is essential that partners are educated and counselled from early on in the CaP journey so that they have a better understanding of their partners' (men with CaP) post-treatment experiences and needs. A partner support group was also recommended by some men, to enable partners discuss and draw strength from each other.

Reflecting on how personal and pastoral prayers helped them to cope on their own CaP journey, a few men suggested that prayer could be included in the support programmes offered to Black men after CaP. The men clarified that whilst there are sensitivities around religious views within the UK, prayer may still be made available as an option within psychosocial support which can be voluntarily accessed by willing Black men along the most difficult aspects of their CaP journey:

"...and then if we have people who have the Christian experience, ...they don't talk about God in this part of the world...but maybe if you have somebody who understands and has a way of presenting it, then if anybody chooses to believe in that they will definitely be lifted, that can be very useful..." (Mr Okri, BA, 58)

To support this idea, another BC man added that complementing prayer with fasting could also potentially help promote healing for men with CaP. He recounted that this helped him to 'starve the cancer cells'. He reiterated the need for medical guidance should any man wish to adopt this suggestion.

4.4 Experiences and needs of partners of Black African and Black Caribbean men with prostate cancer (Paper 3)

Eleven partners participated in the interviews. In-depth analysis of partners' data yielded six themes which were theoretically coded into three broad categories: 1) partner in the passenger seat;

2) care-giving on an isolating journey; and 3) coping as a partner. Findings showed that the majority of the partners felt unrecognised and excluded from their husband's newly diagnosed cancer journey. Although admitting that they were as psychologically impacted by the CaP diagnosis as much as the men themselves, the partners' psychological distress was aggravated by their husbands' and HCPs' lack of recognition for how they themselves had been affected by the CaP experience or what their support needs were. Partners' psychological and emotional distress was further attributed to their feelings of financial insecurity if their husband died from the CaP; communication barriers with their husband regarding how his treatment-related sexual dysfunction was impacting on their marital intimacy; and lack of psychosexual support to help them deal with their sexual challenges as a couple. Whilst acknowledging that they actively provided moral and practical support for their husbands through the CaP experience, the partners reported they had limited support for themselves mostly due to their husbands' reluctant attitude towards public disclosure of the CaP illness. The women coped by expressing sympathy and loyalty for their husbands; praying and exercising spiritual faith; and keeping themselves busy with different activities to distract their minds from their psychosocial concerns. A detailed discussion of these findings is presented in **Paper 3**.



“...It might not have occurred to my husband that this woman, his wife who is taking care of him has some emotional needs as well...”: the unheard voices of partners of Black African and Black Caribbean men with prostate cancer

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Abstract

Purpose Evidence suggests that partners of men with prostate cancer (CaP) experience greater psychosocial distress compared with men themselves. However, the experiences of partners of high-risk (1 in 4) Black African (BA) and Black Caribbean (BC) men with CaP remain poorly understood as existing research has predominantly focused on Caucasian populations. This study aimed to address this gap by exploring partners' experience and support needs as influenced both by the specific impacts of CaP, treatment side effects and socio-cultural context.

Methods Using a constructivist grounded theory approach, eight face-to-face, two Skype and one telephone interviews were conducted with eligible partners ($n = 11$). The interviews were analysed using constant comparison following key stages of open, focused and theoretical coding.

Results Three broad categories emerged which described participants' experiences: 'partner in the passenger seat', 'care-giving on an isolating journey', and 'coping as a partner'. Findings showed that BA and BC cultural marital context influenced how partners experienced and traversed the CaP journey. Peripheral involvement in decision-making, communication restrictions, limited access to support and lack of recognition for their experiences and needs further contributed to partners' psychological and emotional distress.

Conclusions Cultural beliefs, behaviours and values should be taken into account when developing psychosocial support for partners and their men with CaP. Specifically providing information focused on partners and including them in the CaP care pathway could help ensure that partners' needs are recognised and improve marital communications. This could potentially help partners and their men to identify acceptable ways of supporting each other throughout the CaP experience.

Keywords Prostate cancer · Black African · Black Caribbean · Partners · Wives · Experience · Grounded theory

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Introduction

Prostate cancer (CaP) is the most common male cancer and affects Black African (BA) and Black Caribbean (BC) men at disproportionately higher rates (1 in 4) than Caucasian men (1 in 8) [1, 2]. Despite improving survival rates, treatments for CaP often come with adverse side effects (such as sexual dysfunction, fatigue, incontinence issues, hot flashes) which significantly alter the psychosocial well-being of affected men and their partners [3, 4].

Describing CaP as a couple's disease, Wittmann et al. [5] highlight the significant role partners play in providing practical and emotional support for men along their recovery pathway. However, there is limited research on how partners themselves are supported to navigate the psychosocial challenges associated with CaP. The currently sparse literature has focused on Caucasian [4, 6, 7] and African American [8, 9] partners and indicates they often experience greater psychosocial distress than the men themselves due to feelings of isolation, communication constraints and unmet support needs. Partners' experiences within higher-risk BA and BC populations remain poorly understood.

Evidence suggests the existence of cultural influences on how men and partners experience and cope with the impact of CaP [9, 10]. Socio-cultural definitions of gender role and identity have also been shown to underpin the existing power structure in BA and BC relationships in which traditional hegemonic masculinity constructs culturally situate men in a more dominant position than women [11]. These, coupled with the younger age and advanced stages at which BA and BC men are diagnosed with CaP, further suggest that partners within these populations may have unique psychosocial needs which should be addressed in a culturally sensitive way [12, 13]. Therefore, an in-depth exploration of the experiences of partners of BA and BC men with CaP could help inform the provision of appropriate support to improve their psychosocial well-being along the CaP journey.

This article reports partner data from a larger study which focused on exploring the experiences, psychosocial needs and how best to address them after CaP treatment for both BA and BC men and their partners. The aim of this article is to highlight these partners' experiences and support needs, uniquely influenced by the interaction of CaP, treatment side effects and socio-cultural context.

Methods

Study design

A qualitative design using constructivist (co-construction of knowledge through researcher-participant interactions) grounded theory methodology was used [14]. Purposive

sampling (including snowball) enabled the identification and initial access to the 'hard-to-reach' (difficult to access) [15] study participants at different locations in England (Greater London, South and East Central England). Theoretical sampling (in-depth exploration of initial data in later interviews until fully conceptualised) was subsequently used. Between October 2016 and March 2018, potential partners were identified through men who participated in the study, by healthcare professionals (HCPs) at three National Health Service (NHS) hospitals in England and by networking with other colleagues. Regardless of their ethnicity (self-reported by participants) and gender, partners were included if they were in intimate or marital relationship with BA and BC men who had undergone at least 3 months' active treatment for their CaP; resident in the United Kingdom (UK); aged 18 years and above; and able to read, speak and understand English. Partners of men receiving palliative care were excluded because their needs were perceived to be beyond the scope of the study. Eligible and willing partners were provided with an information pack explaining the implications of their involvement. Once written informed consent was received, interview arrangement was agreed with the participant. The study is reported following the Consolidated Criteria for Reporting Qualitative Research (COREQ)'s guidelines [16].

Ethical considerations

Institutional and national ethical approvals were obtained. Interview transcripts were anonymised (using pseudonyms), and all necessary data protection procedures were observed to protect participants' confidentiality.

Data collection

Semi-structured interviews were used to collect rich, in-depth data. A semi-structured topic guide was developed (Table 1) which was informed by the literature and study participants themselves. After the initial interview, the topic guide was subsequently modified to enable in-depth exploration of emerging categories in further interviews. Theoretical sampling guided data collection until saturation was achieved (when emerging categories were fully conceptualised and no further data was required) [14]. Interviews were conducted face-to-face at different locations in England either at each participant's home or place of work (private office), or via telephone or Skype. The interviews, which were audio-recorded and lasted between 30 and 90 min, were conducted by the first author (OB) who is a BA woman with no prior relationship to any of the study participants.

Table 1 The semi-structured topic guide

Sample initial open-ended questions based on research aims and objectives

1. Experience of being a partner to someone diagnosed and treated for CaP
2. Impact of men's CaP on self and marital relationship
3. Cultural implications of husband's CaP within their and husband's (if different) cultural contexts
4. Support experience and psychosocial needs for self as a partner
5. Suggestions on how to address the needs identified in 4
6. Demographic details

Sample open-ended questions on modified topic guide as informed by emerging categories

1. Marital communications and decision-making process in cultural context
2. Personal coping mechanisms
3. Impact of limited disclosure of the CaP on support experience
4. Dealing with sexual challenges

Data analysis

Interview transcripts were organised using NVivo 11 software [17]. Using constant comparison, open coding of the first interview using gerunds (action words) in participants' narratives helped to identify gaps requiring further exploration in subsequent interviews. A more conceptually focused coding followed where relationships, similarities and differences between concepts were iteratively explored and compared with new data, thus probing participants' psychosocial inclinations, responses and processes. Theoretical coding enabled the grouping of similar concepts into categories which were explored in greater detail until theoretical saturation was achieved [14].

Rigour, credibility and trustworthiness

To ensure rigour, credibility and trustworthiness, data were independently analysed by four of the authors (OB, BML, HM and EMcC). Differences in opinion were discussed in-depth and triangulated through expert validation [18] involving a fifth author (DW) to consensually agree on findings. Keeping reflexive and analytical memos enhanced theoretical sensitivity whilst iterative data collection and analysis facilitated the validation of the researchers' interpretation of emerging categories from participants to ensure findings were grounded in their data [14].

Results

Overview

Theoretical saturation was achieved after 11 interviews. All the 11 partners approached for the study consented to be interviewed. Of these partners, seven were recruited by

snowballing through men with CaP who participated in the larger study, whilst four were recruited by purposive sampling through HCPs ($n = 3$) and researcher's networks ($n = 1$). Eight of the interviews were held face-to-face, two were conducted via Skype whilst the remaining one was conducted over the phone. Although gender was not applied as an eligibility criterion, no male partners was identified. All partners were female, aged between 41 and 88 years old and married to either a BA or BC men with CaP. The majority of the women ($n = 7$) were of the same ethnic background as their husband with CaP. Table 2 presents the partners' demographic details.

Six themes were identified which were theoretically coded into three broad categories: (1) partner in the passenger seat, (2) caregiving on an isolating journey and (3) coping as a partner. Relevant quotes are provided in Table 3 to support findings reported under each of these themes.

Table 2 Demographic details of partners interviewed for the study ($N = 11$)

		Partners (n)
BA (3)	Nigeria	1
	Ghana	2
BC (4)	Jamaica	2
	Barbados	2
White (4)	British (WB)	2
	Irish (WI)	1
	Spanish (S)	1
Age (years)	< 45	1
	45–55	5
	56–65	2
	66–75	2
	> 75	1
Length of time married to their husband with CaP	< 20 years	4
	21–30 years	2
	31–40 years	3
	> 40 years	2
Educational level	Below graduate	3
	Graduate	4
	Post graduate	4
Type of treatment husband had for his CaP	Robotic surgery	5
	Brachytherapy	3
	Surgery + radiotherapy	1
	Radiotherapy + hormone therapy	1
	Cryotherapy + hormone therapy	1
Length of time since husband was treated for CaP	Ongoing long term treatment	3
	< 1 year post treatment	5
	1–5 years post treatment	3

Table 3 Some relevant quotes from study participants

Main themes	Supporting quotes
1. Partner in the passenger seat	
a. The unrecognised co-patient of prostate cancer	<p><i>i</i> “...I would prefer, my husband to be more interactive, more communicative than he is, something is poking you then talk to me about it but I tend to be the one that has to draw out everything ... I guess any problems will be on his side because he tends to hold his feelings back... (long pause), it hurts...” (Mrs Freda, BC, 62)</p> <p><i>ii</i> “... I was very worried but I did not show it to him at the time because he needed a supportive person... I wasn't sure how it will affect him being a man because, you are not really told about that sort of thing... I think information is important and especially if you know some people especially women if they are younger, if they do have quite a good sexual relationship with their husband, how it will affect their relationship, you know because nobody really tells you anything like that, you are not really supported with that...” (Mrs Beth, 51, WI)</p> <p><i>iii</i> “...he was acting as if he was the only one who had been through the diagnosis...I could argue my stress has been more, I used to say to him, we have both been very very stressed and he said well you do not know what you are talking about, I do not think he ever, I do not think he ever grasped the level of stress I was under the whole time...” (Mrs Grace, 50, BA)</p> <p><i>iv</i> “...I think if we have an avenue, perhaps as you have come, for the person to talk to the two of us so as to extract this type of conversation, because when you are in a situation you want to see that pain from your own point of view alone, it might not have occurred to him that this woman that is taking care of him has some emotional needs as well, has some needs that are not being met as well, if it comes from an outsider, it will be very effective because if it comes from me, he will say you this woman you have come again, you are always complaining and whining, but if someone else says it, if a counsellor or psychologist says that in the presence of both couple I think it will be very helpful...” (Mrs Julie, 61, BA)</p>
b. Partner position in the back seat in decision-making	<p><i>i</i> “...he had pretty much made his decision before he came to me, he had already made his decision, he very much owned the illness and did not want to share, I will say did not want to share the burden ...” (Anna, 49, WI)</p> <p><i>ii</i> “...I do not think African men, I do not think they like being told because, culturally it's like they tell people what to do, they do not like being told so ...” (Mrs Grace, 50, BA)</p>
c. Partner acknowledging an ‘elephant in the room’	<p><i>i</i> “...and I think because we had a very straightforward sexual relationship which was based on penetration and mutual satisfaction, neither of us was particularly skilled in any other kind of play really, I find that I am actually very anxious, because he is not getting an erection very quickly, maybe he is not finding me attractive or I am not doing what I should be doing I feel that I have not got the skills to help him, so that makes me extremely anxious, I guess anxious is not good for your libido but yea I am struggling with that...” (Mrs Helen, 52, WB)</p> <p><i>ii</i> “...I was obviously very worried because I knew then he had to have operation, I knew then that would affect us, because in many respect not just as a man but he is a very active, strong person, he is also the main breadwinner, you know he's also head of the family...he was always the strong male of the family, you know, so it was how it would affect everybody else and that was quite you know, worrying for me...” (Mrs Beth, 51, WI)</p> <p><i>iii</i> “...how long will he have to live, for instance the issue of will, what is going to happen to me, in African set up, you dare not mention it to your husband at that time, because it would mean you are thinking ah ah so that was the major one but with an English person they are free to talk about it, they can seek help, but I have not been able to, with him you dare not, so I was, I felt boxed in ...” (Mrs Julie, 61, BA)</p>
2. Care-giving on an isolating journey	<p><i>i</i> “...he did put an embargo on me discussing it with my friends... because my natural instinct would have been to discuss it, I think it was so sensitive to him, you know to his identity really, he did not want me to be talking about it with them so I really had to take it inwards, there wasn't anybody to talk to about it...” (Mrs Helen, 52, WB)</p>
3. Coping as a partner	<p><i>i</i> “... well in the Caribbean to be quite honest, you just stick together, so I guess it's the same thing there as it would be here you know, you just have to stick together, support each other...that's it...” (Mrs Debbie, 88, BC)</p> <p><i>ii</i> “...because I was reassured that he would be ok, he would be fine and through prayers...having prayers... we believe er, I believed in healing...” (Mrs Freda, 62, BC)</p>

Partner in the passenger seat

This category describes the peripheral position in which partners of BA and BC men with CaP were placed along their

husband's disease journey. The three themes which contributed to this category are: ‘the unrecognised co-patient of CaP’, ‘partner positioned in the back seat in decision-making’, and ‘partner acknowledging an elephant in the room’.

The unrecognised co-patient of CaP

Findings showed that the majority of the participants felt unrecognised and excluded from their husband's newly diagnosed cancer journey. This was mostly attributed to the men not sharing their concerns about their CaP illness with their partner and also lack of information from HCPs to specifically address partners' needs. Narratives from some of the women showed that although they accompanied their husband to his clinical appointments, they were minimally involved in the conversations that took place. Other women noted they did not attend clinical appointments with their husband because the men preferred to attend alone, insisting that they could take care of themselves. Only a few of the women reported being actively engaged e.g. scheduling their husband's appointments, taking notes for them during consultations and helping the men to search for information online when asked. For many of the women, they reported that they only were given information as much as their husband was willing to share about his CaP. Such women described this as emotionally hurting (see supporting quote at Table 3, 1aⁱ).

The majority of the women highlighted their desire to be well-informed along the CaP journey as they felt psychologically impacted by the diagnosis as much as the men themselves. The women described how they were psychologically affected in terms of feeling shocked at their husband's CaP diagnosis; worried about the potential consequences of the disease on their individual, marital and family lives; having uncertainties around recovery outcomes and processes; and lacked information on how best to support themselves and their husband through the disease trajectory (see supporting quote at Table 3, 1aⁱⁱ).

The psychological and emotional impact of the CaP on partners was not recognised by the men or HCPs. For example, a participant expressed disappointment at her husband's exclusive focus on his illness without showing much insight or acknowledging how the CaP had significantly affected her as his partner (see supporting quote at Table 3, 1aⁱⁱⁱ). Women's perceptions were also that HCPs showed limited awareness and interest in partners' experiences and needs. This seemed to compound the women's distress as they were further pushed towards a peripheral position on the CaP journey. Clarifying this further, the women said they were frustrated at the current lack of information and professional support focused on them to help deal with their psychological and emotional concerns as partners of BA/BC men with CaP. The women suggested that HCPs specifically engaging and supporting partners of CaP patients could facilitate coping by reducing isolation and uncertainty and also help sensitise men towards the unmet needs of their partners (see supporting quote at Table 3, 1a^{iv}).

Partner positioned in the back seat in decision-making

Partners noted that treatment decisions and management of post treatment side effects were led by their husbands who also discretionally determined how much they (partners) were involved in these processes. The women's level of involvement varied in this regard. Few partners acknowledged that there was shared decision-making which enabled them to provide side-by-side guidance and support, making them feel included in their husband's disease journey. However, many partners expressed feelings of exclusion as they reported that their husbands took sole ownership of their CaP and exercised an autonomous right to steer treatment and recovery decisions along their preferred routes whilst they (wives) assumed a background supporting role (see supporting quote at Table 3, 1bⁱ). Some women explained that their husband's controlling attitude towards their illness mirrors the men's position as the head of the family and natural leaders in their nuclear and extended family settings (see supporting quote at Table 3, 1bⁱⁱ).

Partner acknowledging 'an elephant in the room'

The partners reported that their husband's sexual dysfunction after CaP treatment had impacted on the intimacy of their relationship and they found communications on this subject very difficult. Some women reported a substantial decline in the frequency of their sexual relationship since their husband was treated for CaP and felt uncomfortable initiating conversations with their husbands regarding this impact, therefore the subject was not discussed. This resulted in feelings of frustration for the women. The women mentioned that before CaP, their husbands had always taken the lead in the sexual relationship. The women felt reluctant to initiate sex and change this routine as they felt their husbands' personal self-esteem could be affected. The current lack of psychosexual support to help couples deal with anxieties related to sexual problems in their marital relationship was also a source of concern for many partners (see supporting quote at Table 3, 1cⁱ).

Within the marital relationships, women commented that there were communication challenges about certain issues. For example, some women (across the White and Black ethnic origins) noted they felt insecure thinking about the possible economic impact on them and the wider family if their husband died from his CaP illness (see supporting quote at Table 3, 1cⁱⁱ). These issues however were not discussed. Describing their husband as the strong male and main breadwinner for the family, some women's concerns were heightened where the man had not prepared a will prior to his diagnosis and they (women) perceived the subject as too sensitive to discuss (see supporting quote at Table 3, 1cⁱⁱⁱ). Whilst open

communication continued to be a priority need for the women, they expressed frustration that their husbands seemed unprepared to take this on.

Care-giving on an isolating journey

Partners consensually described that although they actively provided moral and practical support for their husband through the CaP experience, they themselves had limited support. The women reiterated that their husband's reluctance to disclose the CaP diagnosis among wider members of their social network constrained their (women's) access to the much-needed support for themselves and increased their feelings of isolation. When probed further, the women attributed such reluctant attitude towards disclosure, to the men's ego and personal decision to self-manage their CaP. The women also explained that the CaP threatened their husband's cultural identity as a BA/BC man (see supporting quote at Table 3, 2ⁱ).

Although most of the women admitted they felt obliged to agree with their husband on this stance, having to contain their personal anxieties and concerns without betraying their feelings made the CaP experience very difficult for them. Where their husbands allowed some disclosure, it was limited to immediate family members, employers, close friends and church pastors, all of whom provided moral and spiritual (church pastor) support for them. The women described the support received from such avenues as excellent.

Coping as a partner

Although the women felt 'restricted' in gaining support from family and friends, they had their husband's needs at the centre of their lives. Many of them reported that recognising the impact that CaP had on their husband made them feel sympathetic towards the man. The women further expressed that their unconditional love and loyalty towards their husband made them feel obliged to prioritise his well-being over their own psychological and emotional needs. Older women (aged over 65 years old) reiterated that couples staying with each in good and bad times is culturally ideal within BA and BC marriages (see supporting quote at Table 3, 3ⁱ).

Narratives from many of the women showed that their faith played a central role in helping them cope with their psychological and emotional concerns. They prayed to God that their husband would not die from the CaP and drew strength from believing their prayers were answered. This gave the women comfort and peace of mind from their greatest fear of cancer fatality (see supporting quote at Table 3, 3ⁱⁱ). Women also stated that they coped by keeping themselves busy with different activities which diverted their minds away from their husband's CaP. Such activities mostly included taking on

additional work loads such as journal writing, reading, exercising, watching television and caring for their own children, and in few cases, grandchildren.

Discussion

Findings from this study suggest that the BA/BC cultural marital context uniquely influenced participants' experiences as they traversed the CaP journey. Unlike a related study involving Caucasian participants [7] where partners were very much involved in their men's health, steering them to seek help and taking centre stage in their care, findings from this study highlight a peripheral involvement of partners in the CaP journey of BA and BC men. Such peripheral involvement was more profound in the area of decision-making, accessing information and communication with the men and HCPs. Their husbands' insistence to maintain secrecy around the CaP diagnosis and cultural restrictions in discussing their anxieties, especially as regards wills and sexual intimacy, also contributed to the participants' emotional distress.

Reiterating the cultural expectations that the man is the head of the family who leads in core areas such as decision-making, sex and bread-winning [19, 20], our study participants recognised how these influenced their husbands' behaviour towards their CaP and the expectations they had of their partners. Evidence highlights the therapeutic effect of open communications in helping couples cope with the psychosocial challenges of CaP through shared decision-making and mutual understanding [6]. However, it seemed that adherence to traditional hegemonic gender ideals which predominantly underpin the cultural beliefs and values of BAs and BCs [20, 21] may have made such open communications very difficult for participants in this study.

Whilst it has been suggested that marital intimacy can be improved post treatment for CaP where partners feel comfortable to take the lead in initiating sexual activity [5], previous evidence showed that partners are often reluctant to assume this role so as not to further upset the man whose self-esteem may have already been affected by the side effects of the CaP treatment [6]. Such reluctance to change roles also resonated with partners in this study. Despite their desire for improved marital intimacy, the women perceived that trying to lead sexual discussions and activities affected their husband's self-esteem, as this seemed to have hit the core of the men's masculine identity (which is culturally defined by sexual virility and performance) [20]. Moreover, traditional cultural expectations for women to prioritise nurturing roles over pursuit of sexual goals whilst men lead core activities and decisions (including sex) may have further constrained partners of BA/BC men with CaP from taking the lead in this regard [19].

It is also pertinent to note the younger age at which CaP occurs in BA/BC men [1], which further suggests that their

partners may be younger, as evidenced in the majority of women in this study being below the age of 65 years. This indicates that many of these couples may be at the age where sexual activity is a significant part of their routine lives. Hence, the psychosexual impact of sexual dysfunction on the man and consequently on his partner cannot be underestimated. The World Health Organisation (WHO) defined sexual health as a state of physical, mental and social well-being in which individuals are capable of having pleasurable, mutually acceptable and satisfying sexual experiences and relationships [22]. Therefore, empowering partners to help their men navigate post treatment sexual challenges through mutual understanding and resolution without undermining their cultural values could potentially enhance couples' psychosexual well-being after CaP treatment.

Whilst the use of religious faith and physical distractions as coping strategies are consistent with previous reports on partners among African American [9] and some Caucasian [23] populations, women's description of sympathy and loyalty as coping strategies may be novel in this study. Hegemonic femininity constructs within BA and BC cultures epitomise women as natural caregivers who are expected to be subordinate, submissive, dependent and more emotionally expressive than men [21]. Such feminine ideals combined with being in long-term marital relationships with their husbands may have enhanced our participants' sensitivity to the men's illness experiences and enabled them to prioritise men's well-being over their own need for improved marital communication and sexual intimacy. Contrary to findings from previous studies where some BA and BC men with CaP had expressed fear of being abandoned by their wife if they were unable to meet their sexual obligations post treatment [24], expressions of sympathy and loyalty in this research suggest that wives' opinions may differ in this regard. Cultural values placed on marriage within the BA and BC cultures propounds that married couples are highly regarded and respected within these communities [11, 25]. Despite acculturation assumptions [26], findings from this study indicate that women married within and into the BA and BC communities may continue to uphold existing idealistic cultural values regarding marital commitment and loyalty regardless of living in a western society (UK). Although serving as coping mechanisms, such traditional cultural values may have further undermined the women's feelings of unhappiness, isolation and exclusion.

Implications for practice

When compared with some previous related studies among Caucasian [7] and African American [9] populations, it appears that the implications of CaP may be more complicated for partners within BA and BC populations due to complex socio-cultural influences. This suggests the need for increased

cultural awareness and competency among health and support care providers in the development and delivery of psychosocial support (such as information, counselling services) to these populations. In a clinical setting, it is important to recognise men's culturally informed leadership roles and at the same time acknowledge the significant impact of CaP on partners' psychosocial well-being. Without undermining their role as the head of the family, BA/BC men can be educated about the needs of their partners to be actively involved and also supported along the CaP journey. Inclusive support care which involves partners and incorporating comprehensive psychosexual support could potentially encourage willing men to develop empathy for their partners experiences; help couples to engage in open communication to mutually understand their concerns, and identify how they can support each other through the most challenging aspects of their CaP experiences.

Bearing in mind the centrality of their husband's recovery, and the well-being of their partner's, there is further need for holistic interventions delivered in a culturally sensitive manner to address the influence of CaP on the sexual health and mental well-being of men and partners both as individuals and as a couple [22]. This could help ensure that the sexual rights of both the man and his partner are still respected and preserved amidst inevitable limitations imposed by the man's CaP illness [22]. These measures could potentially help to improve the psychosexual and psychosocial well-being of the women and also that of their husband with CaP.

Study limitations and directions for future research

This qualitative study makes a significant contribution to knowledge by being one of the first to bring to fore the unheard voices of some hard-to-reach partners of BA and BC men with CaP. Insights from this study can inform the provision of culturally sensitive support for these under-researched population. Although a qualitative design does not make these findings generalisable, clinicians can refer to them for potential transferability to similar settings. The lack of availability of same-sex partners limits the transferability of the findings to such BA/BC couples. Whilst the women were heterogeneously distributed across BA, BC and White ethnic backgrounds, the majority of them being younger, well-educated and in long-term marriage with a BA or BC man may have contributed to the observed homogeneity in their narratives. Concepts identified in this study can serve as a starting point for quantitative research that can help explicate how much of partners' experiences can be attributed to culturally informed gender, socio-economic and marital stereotypes.

Conclusion

This study identified the cultural definitions of masculine and feminine roles and identities within the BA and BC marital context as influential on partners' psychosocial experiences of CaP. In addition to previous research findings that partners may feel isolated and have limited psychosocial support, these female partners were further handicapped by cultural norms such as men's assumption of a leadership role and restrictions on public disclosure of the CaP illness. Regardless of having unmet communication, information and psychosexual support needs, the women coped by prioritising their husband's well-being over their own needs. Psychosocial support should engage couples in problem-solving that would recognise this socio-cultural context and help them navigate their communication and sexual challenges after CaP treatment. Areas for further research were also identified.

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Compliance with ethical standards

Ethical statement All procedures performed in this study were in accordance with the ethical standards of the institutional and national research committees and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. Informed consent was obtained from all individual participants included in the study.

Conflict of interest The authors declare that they have no conflict of interest.

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4.5 Healthcare professionals' perspectives

Eleven HCPs participated in two interviews and two focus groups (5:4). Four themes emerged from the analysis of HCPs' data which described their experiences of caring for BA/BC men with CaP and their perceptions of the men's support needs. The themes were theoretically coded into two broad categories: 1) HCPs recognising the difference; and 2) Identifying Black men's support needs.

4.5.1 Healthcare professionals recognising the difference

Representing different disciplines within the uro-oncology healthcare team, the HCPs reiterated that during their several years of dealing with CaP patients, BA/BC men are culturally different in their attitude and response to CaP. Three themes contributed to this category: *'Black men delaying to take up CaP treatment'*; *'Black men prioritising natural potency'*; and *'Exclusion of partners'*.

4.5.1.1 Black men delaying to take up prostate cancer treatment

HCPs had different views regarding the promptness of Black men in taking up treatment for CaP. The HCPs stated that compared with Caucasian men, young Black men often delayed taking up radical treatment for their CaP thereby resulting in the cancer having advanced by the time they eventually present for treatment:

"...it struck me that actually we get a relatively high proportion of young black men who are offered the chance of cure, who disappear. They disappear and then they are presented back with metastases and we see these men at the multi-disciplinary meetings and then they're on to palliative treatment which is a terrible shame in young men..." (HCP 1, focus group 1, consultant urologist)

The HCPs noted that it appeared these men had their own ideas regarding their treatment plan such as travelling to their home country for alternative medicines or consulting with their peers who have undergone a similar journey prior to taking up any treatment procedure. HCPs added that Black men seem to place high priority on their sexual performance and virility in which a CaP diagnosis is often perceived as ‘emasculating’ within their cultural setting. They suggested that this could be another possible reason for delays in treatment uptake among BC and BA men diagnosed with CaP:

“...The only people I’ve seen who have refused any treatment are all black men and it is about their sexual function. It’s not, it doesn’t tend to be about the cancer or their urinary symptoms, it tends to be in my experience their sexual function which is really important to them. I’ve had people say to me I don’t care if I die, I’d rather die than lose my sexual function...” (HCP 5, focus group 1, urology clinical nurse specialist)

The HCPs added that some of the Black men they had cared for seldom asked questions and had to be prompted to elicit their concerns or information needs.

4.5.1.2 Black men prioritising natural potency

With regards to supporting men to manage their post-treatment side effects (especially sexual dysfunction), the HCPs stated that whilst psychosexual counselling services are currently lacking in post-treatment routine care, clinical aids are often offered to help men deal with treatment-related sexual dysfunction. They identified that Black men are often reluctant to embrace such aids as they seem to take pride in their ability to achieve natural potency:

“...But, what strikes me, those who I have spoken to about these alternative ways to generate an erection is that that’s not palatable. Even the implant where they have a button that they press which fills the carpal bodies or the implant with fluid so that they get an erection, that doesn’t seem to be acceptable to these chaps. My feeling is that there is a need to be naturally potent...” (HCP 1, focus group 1, consultant urologist)

4.5.1.3 Exclusion of partners

Further describing how BA/BC men are culturally different from Caucasian patients, the HCPs highlighted a general reluctance among BA/BC men to involve their partners in their CaP journey. Some HCPs had probed some men for their reasons why they did not want to involve their partners in their CaP journey. In response, some men stated that CaP was their personal problem which they did not want to bother their partners with. For example, one HCP recalled her experience with a Black patient who narrated that withholding information about his CaP diagnosis from his wife and children was necessary to protect them from worrying about him especially as the news could worsen his wife's current ill health:

"...rarely bring their partners... I had a case scenario a young man who was diagnosed, he's 51 or 50, I said bring your wife, he didn't bring his wife when coming for breaking the bad news, eventually when I broke the news he said to me 'when you are sending the letter of appointment to go to x hospital, don't send it to my address, I will come and pick it up' I said why, he said 'I don't want my wife to know' I said why maybe they have concerns for their wives, he said 'my wife has got high blood pressure and if she gets to know, it's going to make it worse', he said 'oh my children are doing GCSE, I don't want this to destabilise them...' (HCP 6, uro-oncology nurse)

Some HCPs perceived that some men's preference to exclude their partners from the CaP journey may also be due to the 'emasculating' tendency of CaP which has cultural implications for the men's masculine identity as sexually potent individuals. The HCPs explained that men who are unable to meet up with their cultural masculine ideal to be able to father children may be stigmatised within their marital settings:

"...So, I've had men express that (sexual virility) and then in this radio phone-in, women also expressed that...So, the whole thing kind of reinforced itself... It's tied up with a kind of idea of manhood, its tied up with idea of being able to have children even though you're nearly 70, it's tied up with your position in society and how people who regard you as not being a man if they knew... because they would be seen as less of a man... the whole idea of race is tied up to your identity as a man..." (HCP 4, focus group 1, consultant urological surgeon)

The HCPs were further probed for what they perceived as the support needs of Black men with CaP and how these needs could be addressed.

4.5.2 Identifying Black men's support needs

The HCPs elaborated that within the healthcare agenda, there is need for better understanding of the BA/BC culture, to identify what the men's specific priority needs are and to take these into account when developing post-treatment support for the men. For the majority of the HCPs, their participation in the research was motivated by a desire to better understand the cultural perspectives of this group of patients in order to support them better along the CaP journey. Noting the significance of sexual function to the cultural identity of BA/BC men, some HCPs reiterated men's earlier views on the need to incorporate psychosexual counselling services as part of routine care for the men. The HCPs added that using channels or HCPs whom the men can culturally identify with to deliver psychosocial support care may also potentially help to promote better engagement with the BA/BC with CaP:

"...I think you should have an understanding, definitely, of their culture, the culture of that group of patients, what's important to them, and not be blonde, middle-class, lady, basically. Do you know what I mean...?" (HCP 4, focus group 2, uro-oncology Nurse)

Some HCPs suggested the use of individual peer champions whom the men can culturally identify with within their community as a beneficial strategy to support Black men with CaP. The HCPs clarified that Black men's reluctant attitude towards public disclosure of CaP suggests that individual peer support may be preferred by the majority of them (men) compared with support delivered in group settings:

"...Yeah, so, I think that lots of Black Afro-Caribbean, they get guidance and support from their friends, their peers, I don't think that they would ever come to the hospital, to a group and talk about that, not really, that I've noticed..." (HCP 4, focus group 2, urology research nurse)

Noting how BA/BC men seldom involve their partners in their CaP journey, the majority of the HCPs highlighted the need to continue to encourage the men to engage more with their partners along the CaP journey, and as early as when they are diagnosed. For example, an HCP explained that some men are ignorant of the implications of not involving their partners in their disease journey and may do so if properly educated. The same HCP recounted how a BA patient who was initially reluctant to inform his wife about his diagnosis later heeded her (HCP) advice and informed his wife. He was grateful to the HCP afterwards as he noted his wife did not take the news as badly as he had anticipated:

“...he thanked me and he said to me ‘you know what, I have spoken to my wife and she took it very well, just post any letter to my home, no problem ...’” (HCP 6, uro-oncology nurse)

The need to increase education and awareness of CaP within the BA/BC community was also suggested by some HCPs as a potential way of helping to deal with stigma associated with the disease and promote a more positive attitude among the men towards accessing post-treatment support. In addition to the men’s need to access support from their partners and peers, some HCPs further identified that Black men’s religiosity and the influence of the church on them suggest they could access further support through this avenue:

“...There’s a lot of influence within the church, where they go to...they are very specific, their local churches for their own community. They do, they seem to go around, one says this worked, they all try. I think there is some kind of influence in that...” (HCP 2, focus group 2, uro-oncology research nurse)

Although the HCPs could not comment much on partners’ specific support needs as the majority of healthcare focuses primarily on the men, they reported that they do try to include partners in discussions whenever couples attend consultation together. The HCPs also agreed with some men and partners’ narratives on with the need for partner-specific support.

4.6 The substantive theory: ‘man in the driving seat’

There are variations in the definitions of a theory (for example, formal or substantive) depending on its purpose and the philosophical perspective from which it is viewed (Charmaz 2014). Following suggestions by Thornberg and Charmaz (2014), it was pertinent to define what theory was developed in this research and how it was constructed. A substantive theory was developed by iteratively comparing similarities and differences between categories which emerged from the three data sets with each other and with additional data until theoretical saturation was achieved. Similar categories were subsequently aggregated to form the core category ‘*man in the driving seat*’ which in relation to its associated categories (Figure 3), theoretically explains the basic social processes involved in the CaP experiences of BA/BC men and their partners and provides a contextual understanding of this under-researched phenomenon. Details on how the theory was developed are provided in Chapter Three, section 3.3.7.5.

Moving the data beyond description to analytical interpretation, ‘*man in the driving seat*’ provides useful insights into why BA/BC men with CaP need to ‘own their illness’ while their partners were placed in a peripheral position along the CaP journey. The reasons seemed to be tied to the men’s desire to resist the ‘emasculating’ tendency of CaP from stripping them of their culturally informed roles and identity as leaders in decision-makings, sexual activities, and bread-winning and in ensuring the general welfare for themselves and their families. Narratives from the men, partners and HCPs substantially attested to this gendered definition of masculine role and identity within the BA and BC cultural contexts and this seemed to have significantly shaped how the men and their partners transversed the CaP journey.

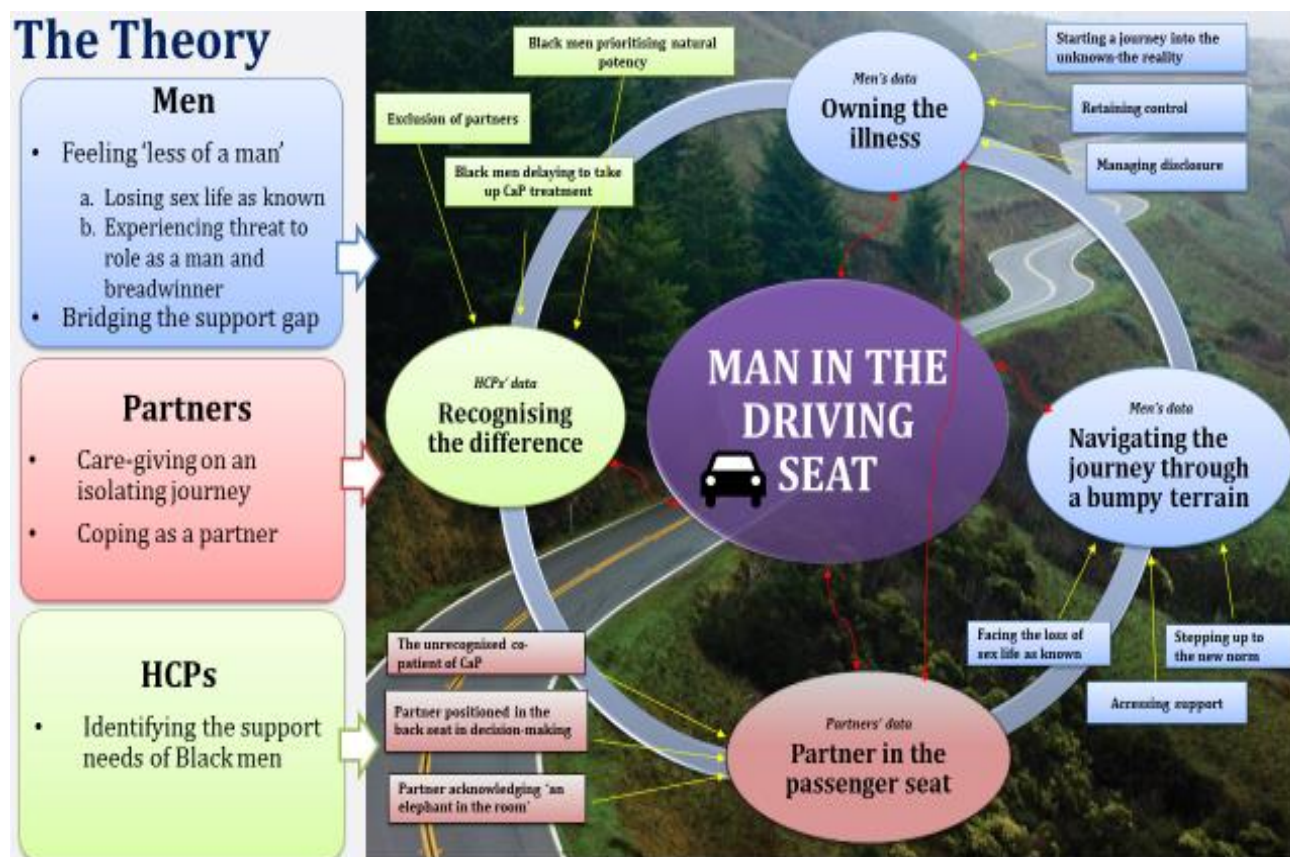


Figure 3: Theoretical Model Showing the Core Category, Associated Categories and their Contributing Themes from the Men, Partner and HCPs' Data.

There appeared to be a hierarchy of power within the BA/BC context in which the men were dominantly positioned as leaders, whilst their partners mostly operated from a subordinate and 'accepting' position:

"...because we take our wives to be our slaves, so the wife has no right, if I am a vegetarian, the wife should eat a vegetarian food as far as I am concerned, if I am not in the house she can eat the food but I shouldn't know ..." (Mr Tom, BA, 88)

Reflecting this norm, narratives from the men, partners and HCPs highlighted an autonomous and self-driven behaviour from the majority of the men towards help-seeking for diagnosis, treatment and managing of post-treatment side effects:

“...I think it was my decision first, it was my decision primarily and then she backed me up, it wasn’t as if I sat down and said these are all the various options, I said there are all these various things but this is what I’m going to do... being the only son and growing up without a father you learn to take decisions, I lead even at work, so I’m quite, some people say I find it quite difficult to delegate...” (Ben, BA, 50)

“...He very much owned his illness and didn’t want to share...” (Mrs Anna, WI, 49).

“...it struck me that actually we get a relatively high proportion of young black men who are offered the chance of cure, who disappear...” (HCP 1, focus group 1, consultant urologist)

‘Man in the driving seat’ further helps to understand the men’s decisions to take responsibility for themselves, their healthcare, and family welfare amidst the threat of the CaP disease. For example, some men explained that their decision to minimally involve their wives in decision-making regarding their CaP was because they did not want to burden them (wives) with their illness but to allow them (wives) to focus on other things which they (men) considered should be their wives’ priorities (for example, childcare and their jobs). Some partners added that dominance through that personal responsibility and delegating was consistent with the identity and role of BA and BC men within their families and wider societies:

“...I don’t think African men, I don’t think they like being told because, culturally it’s like they tell people what to do, they don’t like being told so ...” (Mrs Grace, BA, 50)

HCPs further validated this behaviour as they recounted that most Black men often attend consultations alone, with some men whom they have cared for insisting on not informing their partners about the diagnosis at all:

“he said ‘I don’t want my wife to know’ I said why maybe they have concerns for their wives, he said ‘my wife has got high blood pressure and if she gets to know, it’s going to make it worse...’” (HCP 6, uro-oncology nurse).

Further insight gleaned from the substantive theory ‘man in the driving seat’ relates to the men’s controlling attitude and behaviour towards their illness especially with regards to disclosure and

marital communications which they seemed to guard and only share if and only when they wanted to. Such controlling attitude was also reflected in the men's behaviour towards the management of their post-treatment side effects:

"...and because of the symptoms that I am experiencing now, I think that they (HCPs) can be a bit frustrated with me because I haven't done what they asked me to do, or do it in their way and I think sometimes that could be an issue because if I continue complaining about the pain and stuffs like that, they can say I am not following their advice ... and sometimes I feel like I don't want to be pressured by anybody, at the end of the day it is my decision, it is my body, because all the suggestions they (HCPs) offered to me I don't want the suggestions, at my age I feel like you know, I will like to go on my terms and I don't want to be coerced into anything I don't want to do ..." (Mr Yusuf, BC, 68)

Some partners also commented that their husbands autonomously took decisions on how they wanted to deal with their sexual problems, deciding on what medications to take without consulting with them (partners) for mutual discussions on how best to handle the situation as a couple:

"...so without letting me know, he bought erm Viagra tablets a couple of times..." (Mrs Julie, BA, 62)

This attitude was also noted by the HCPs who observed a difference in how their BA/BC patients responded to sexual dysfunction, highlighting the men's reluctance towards the use of alternative approaches. The gendered definitions of the men's and their partners' roles as depicted in the substantive theory '*man in the driving seat*' also seemed to have contributed to the observed discrepancies in their understanding of each other's priority needs after CaP treatment, despite that most of them had been married for a long time (over ten years). In some interviews, the men's perceptions were that their partners were strong and coping well, primarily drawing strength from supporting the men:

"...my wife I think her support is her being a strong woman, as an independent woman, her personal strength within herself ... she is a strong-willed person and strong character and I think that those are the strengths that have driven her through this challenge, you know ...she likes to do everything behind the scene kind of thing, she said 'your job is to save men, my job is to save you; that's what she says, I can't ask for a greater statement than that really..." (Mr Harry, BC, 60)

Whilst few of the men recognised the need for their partners to have support, the majority seemed oblivious of how their partners were impacted by the CaP experience or what their (partners) specific support needs were. Narratives from some men and partners identified that in many instances, the women's psychological and emotional needs such as unmet communication, information and sexual needs were not recognised by the men:

"...er, she does not have any needs..." (Mr Dave, BA, 62)

"...It might not have occurred to him that this woman that is taking care of me has some emotional needs as well..." (Julie, BA, 61)

'*Man in the driving seat*' further seemed to account for why the majority of the men seemed to portray more positive than negative coping for their CaP illness (compared to what partners and HPs reported in their data). It appeared that it was important for the men to portray that they were being strong and handling their disease experience well without revealing much vulnerability. Although often overlooked due to this stereotypical portrayal of 'machoism', findings from this study suggest that being in the 'driving seat' can be quite isolating and physically and mentally challenging for the men due to the responsibilities and expectations associated with the position. In-depth probing in further interviews with the men and partners also indicated that beneath the men's portrayal of 'machoism', they were not happy with the challenges the CaP posed to them, but they felt pressured (by themselves) to suppress such feelings. For example, there were indications of helplessness by some men regarding difficulty in discussing their sexual concerns with their partners. This resulted in feelings of unhappiness for the men and also frustration for their partners:

"...I don't know it's just sometimes I just don't really want to talk about it and she is not too happy about my attitude you know... I probably don't know what to say, you know because

I am not quite happy about the whole situation, I am not happy but there is nothing I can do about it... ” (Mr Mike, BC, 68)

“...I tell him all the time about communication but it’s a big issue... ” (Freda, 66, BC)

The men’s acknowledgement of the threat of CaP to their masculine roles and identity especially in the areas of sexual function and breadwinning further highlights that living with a CaP illness could place them in a vulnerable and challenging position, which they may be unable to reveal but should be recognised by HPs:

“...because I need to be there for my family I need to be able to provide for my family ...I have to, as a man, look to my family, ok, I have to, if I am not able to have that ability to provide by myself, then mentally, it is destroying me, it will destroy me, erm so there were those type of thoughts... ” (Mr Nelson, BC, 59)

The implications of the substantive theory ‘*man in the driving seat*’ on partners’ psychosocial experiences also cannot be underestimated. The majority of the men putting restrictions on the CaP disclosure, avoiding communications on sexual challenges, and HCPs excluding the women from healthcare support further highlight the isolating position which partners of BA/BC men with CaP are placed along the CaP journey.

4.7 Summary

This chapter reported study findings predominantly focusing on men and HCPs’ data and also the developed theory. Men’s experiences of CaP, their perceived priority support needs and suggestions on how those needs could be addressed were highlighted in the chapter. HCPs’ experiences of caring for BA/BC men with CaP and their perceived suggestions on how best to support the men were also discussed. Lastly the developed theory which provides a conceptual framework to understand the basic social processes involved in the CaP experiences of BA/BC men and their partners was also presented.

CHAPTER FIVE: DISCUSSION AND CONCLUSION

5.1 Introduction

The overall aim of this study was to explore the experiences and psychosocial needs of Black African and Black Caribbean men with prostate cancer and their partners in England. This chapter discusses the study's findings and is presented in three main sections. The first section discusses key findings which emerged from the men's, partners' (**Paper 3**) and HCPs' data. The second section discusses the substantive theory developed in the study. The third and final section discusses the implications for practice, recommendations, and the strengths and limitations of the study. The study's contributions to knowledge and directions for future research are also identified.

5.2 Discussion of key findings from the study

Findings indicated that most of the post-treatment experiences of BA/BC men with CaP and their partners mirrored previous reports on Caucasian and AA men. An intersection between clinical treatment procedures, physical side effects of treatment and gender stereotypes regarding masculinity may have contributed to these similarities. For example, the perception of diminished masculinity due to treatment-related side effects (such as sexual dysfunction) as reported by BA/BC men in this study echoes previous evidence on Caucasian (Cecil *et al.* 2010; McCaughan *et al.* 2015) and AA (Rivers *et al.* 2011) men. Partners' reports on a reluctance to initiate sex in order not to upset the men also resonate with findings on Caucasian groups (Wittmann *et al.* 2014). However, it appeared that the higher prevalence of CaP among younger BA/BC men coupled with hegemonic masculinity beliefs which are predominant within their cultural context may have contributed to some differences observed in how they and their

partners responded to the CaP experience. Such differences seemed particularly pronounced in the areas of: enactment of masculine roles and identities, illness disclosure, coping and accessing support, and partner engagement. Findings are now discussed under five broad themes: threatened masculinity, disclosure of the prostate cancer illness - barriers and concerns, coping and support experiences, partner role and experiences, and delineating cultural differences - healthcare professionals' perspectives.

5.2.1 Threatened masculinity

Study findings suggest that treatment-related side effects posed a threat to men's cultural perceptions of their masculinity. Core values of masculinity within the BA/BC cultural context include: independence (for example, ability to take care of self without depending on others); leadership (for example, leading core decisions in marital relationship such as initiating sex); sexual virility and prowess; breadwinning (for example, being the main provider for self and family); and dominance/control (for example, telling others what to do) (Coomarsingh 2012; Kolawole *et al.* 2012; Owens *et al.* 2015; Odimegwu and Somefun 2017).

Whilst the threat of sexual dysfunction to masculinity has been similarly reported among Caucasian men with CaP (McCaughan *et al.* 2015), there appeared to be a magnified impact of this treatment side effect on BA/BC men. This trend was likewise reported in Rivas *et al.*'s (2016) review of studies, in which AA men reported a magnified impact of sexual dysfunction on their masculine identity compared with Caucasian men. There are postulations that sexual dysfunction may have more psychosocial impact on younger CaP survivors because sexual function and activity are believed to decline with advancing age (Badr and Taylor 2009; Benedict *et al.* 2014). However, findings from this study seem to challenge such assumptions,

especially for BA/BC men. Study findings showed that both the younger and older men seemed to place high value on the performance and reproductive aspects of sex as these seem to shape their feelings of being a complete man. This underscores suggestions by Aggleton *et al* (2015) that cultural context and systems often influence how people define and interpret their sexual experiences.

Evidence related to Caucasian men with CaP (Chambers *et al.* 2015) further suggests that younger men often experience more psychological distress (such as depression and anxieties) after treatment, compared with older men. This has mostly been attributed to: feelings of being afflicted with an old man's illness (Iyigun *et al.* 2011; Chambers *et al.* 2015); greater difficulty in coping with the impact of fatigue on physical activity and work lives (O'Brien *et al.* 2007; Matheson *et al.* 2017); and impact of sexual dysfunction on their masculine value as potent men (Grunfeld *et al.* 2013; Chambers *et al.* 2015). These were similarly reported in this study. However, it appears that for younger BA/BC men with CaP, psychological distress was further increased by the threat of CaP to their cultural role as the main breadwinner within their nuclear and extended families. The economic threat of CaP to men's role as their family breadwinner has been identified as an important source of psychological concern to cancer survivors and their families (Cecil *et al.* 2010; Grunfeld *et al.* 2013). Such concern seemed more pronounced among some of the younger men in this study as the older ones appeared to be less psychologically bothered about the impact of CaP on their breadwinning role. This could be because the younger men were still at their productive work years when they were diagnosed and treated for CaP. The majority of the older men had either retired or neared retirement age and had fewer financial obligations (for example, some had older children who were financially independent). For

younger men who had made financial investments prior to their diagnosis, they also experienced less threat to their breadwinning role.

Whilst lower social class (limited ability to pay for healthcare costs) has been associated with higher psychological distress among AA men with CaP and impact on their access and utilisation of healthcare services (Xanthos *et al.* 2010), this did not seem to be an issue for UK-based BA/BC men with CaP. Rather the economic impact of the CaP illness was associated with the men's ability to continue to fulfil their breadwinning responsibilities to themselves and their dependent families after treatment. Previous studies (Burns and Mahalik 2006; Campbell *et al.* 2012) have highlighted that CaP survivors who uphold traditional masculinity stereotypes often experience poorer psychological outcomes. For example, despite some men showing appreciation that their wives provided some financial cover whilst they were recovering from the CaP illness, this did not substantially reduce their feeling "less of a man" when they were unable to provide for their family due to post-treatment fatigue.

Treatment-related fatigue further seemed to pose a threat to men's ability to maintain their physical fitness which was reported as an essential part of their masculine identity. Supporting evidence from Er *et al* (2017), retaining a fit body image appeared to be an essential part of the men's perception of their masculinity, especially among younger men. Perceptions are that a Black man's sexuality as a strong and virile man is further reflected in a firm and physically fit body and this seemed to inform some men's priority need to regain their pre-treatment physical activity levels in this study. Psychosocial support which incorporates self-regulated physical activity programmes could also be potentially acceptable to BA/BC CaP survivors.

5.2.2 Disclosure of the prostate cancer illness - barriers and concerns

Findings showed that although a few BA/BC men disclosed the CaP diagnosis within their wider social networks, the majority preferred to keep it private regardless of differences in their educational levels and age. The reluctant behaviour of men in this study towards public disclosure seemed to be underpinned by male pride; mythical perceptions that ‘*ignorance is bliss*’ (saving others [for example, children] from worry by not disclosing); and avoidance of stigma associated with a CaP diagnosis. Similar to findings from previous related studies (Mulugeta 2014; Rivas *et al.* 2016), such stigma was mostly attributed to: an embarrassing diagnostic procedure (DRE); a potentially castrating impact of CaP; and potential fatality from the disease. Conflicting views among the men regarding disclosure of the CaP within their religious circle or accessing support from such an avenue also seem to challenge previous suggestions on the potential of delivering CaP support for Black men through their religious leaders and community (Baruth *et al.* 2013; Bamidele *et al.* 2017a). This brings to bare the existence of individual differences among members of the same cultural group in terms of where or how they may access support.

An additional barrier to disclosure which was reported by some men in this study (especially among BA participants) was a desire to retain full control over their personal information and avoid being manipulated by external forces such as witchcraft. The influence of religious-cultural belief in witchcraft on BA/BC men’s behaviour towards disclosure highlights another perspective in their response to the CaP illness. Whereas open disclosure has been predicted to reduce psychosocial burden both for the patient and his partner/carer (Williams *et al.* 2014), men associated it with loss of control over their lives. Attributing a cancer diagnosis to being caused by witchcraft has previously been identified as a barrier to accessing and utilisation

of cancer services among BME groups (Aziato and Clegg-Lamprey 2015; Bamidele *et al.* 2017b; Walubita *et al.* 2018), and highlights how ingrained spiritual beliefs may interact with culture to influence their health experiences, behaviours and outcomes (for example, delayed diagnosis).

5.2.3 Coping and support experiences

Partners' coping and support experience have been discussed in **Paper 3**. Hence this section focuses on the men's coping and support experiences. Evidence from this study suggests that cultural values placed on masculinity within the BA/BC context seemed to influence men's coping and adaptation to the CaP experience. Key findings on the men's coping and support experiences are discussed under four sub-themes: coping through resilience, finding comfort in fatherhood, reluctance to share responsibility for dealing with treatment side effects, and limited utilisation of external support.

5.2.3.1 Coping through resilience

For the men in this study, their portrayal of resilience as their most predominant coping strategy resonates with findings from other related studies both on Caucasian (Sharply *et al.* 2014b) and Black men (Nanton and Dale 2011; Bache *et al.* 2012). Men's resilient behaviour seemed to have been influenced both by their personal desire to be in control of their lives and a masculine dictate to maintain a strong and stoical stance in the face of a challenging situation (Machirori *et al.* 2018). Spirituality and faith have also been suggested as enhancers of resilience among many Black men with CaP (Bache *et al.* 2012; Zhang *et al.* 2015; Rivas *et al.* 2016). This resonated with men in this study as spirituality (which was mostly expressed through personal

faith in God and prayers) was reported to help them deal with their fears of possible cancer fatality and endure post-treatment challenges.

Men who are resilient have been reported to experience reduced psychological distress (for example, anxiety and depression), and resilience has been recognised as a positive coping strategy among CaP survivors (Sharpley *et al.* 2014b; Bamidele *et al.* 2017a). Moreover, providing peer support to others also seemed to increase some men's resilience as this was perceived as a greater cause which motivated them to renegotiate their cultural beliefs around illness disclosure. For other side effects (such as incontinence and fatigue), men also demonstrated resilience by discretionally adopting active coping strategies to deal with the daily challenges of the problems. Resilience has been shown to enhance an individual's ability to adapt to a stressing situation through problem-solving (Greeff and Thiel 2012; Zhang *et al.* 2015) and there are suggestions that resilience training should be increasingly encouraged among CaP survivors (Sharpley *et al.* 2014b). Evidence from this study indicates that psychosocial support which incorporates resilience training and self-management of post-treatment side effects may potentially be useful for BA/BC men with CaP.

5.2.3.2 *Finding comfort in fatherhood*

The constant reference of men in this study to the concept of fatherhood as a demonstration of their masculine identity, further highlights the magnitude of CaP on their sexual lives. However, their constant use of phrases such as '*it is a small price to pay for being alive*', '*it could have been worse*', indicated a mental shift in their focus from the perceived cultural implications of the loss of their sexual potency and virility (effeminate) to moving on with life regardless. The inevitability and chronic nature of treatment side effects may also have

compelled the men to renegotiate their idealistic masculinity beliefs in this regard (O'Brien *et al.* 2007). Men's renegotiation of their masculinity post-treatment for CaP has been similarly reported among Caucasian groups (Maliski *et al.* 2008; Gannon *et al.* 2010; Spendelow *et al.* 2018). Specifically among BA/BC men in this study, ability to father children biologically formed part of the predominant hegemonic masculinity construct which idealised them as sexually potent and virile (Datta 2007; Allen 2016). Having had children prior to their treatment seemed to provide a sense of fulfilment which may have helped them to negotiate their diminished sexual potency after CaP treatment. This supports Connell's (2005) argument that in reality, men's traditional perception and attitude towards their masculine identity may be modified following debilitating illness experiences such as CaP.

5.2.3.3 Reluctance to share responsibility for dealing with treatment side effects

Study findings showed that BA/BC men mostly took personal responsibility for dealing with their CaP treatment side effects (especially sexual dysfunction) as many did not engage their partners in shared problem-solving nor did they seek external psychosocial support. Whilst the men acknowledged their partner's invaluable role in providing moral support and encouragement for them along the CaP journey, there was a reluctance to share their psychological concerns with the women.

Avoiding discussions with partners to explore mutual ways of dealing with post-treatment sexual challenges have been similarly reported among Caucasian men with CaP (Badr and Taylor 2009; Tanner *et al.* 2011). However, for the BA/BC men in this study, cultural values for men to take responsibility for themselves and others (Odimegwu and Somefun 2017), coupled with the impact of sexual dysfunction on their personal self-esteem may have influenced

their reluctance towards partner engagement or seeking external support to manage their sexual problems. Regardless of being aware of their wife's desire for improved marital communications to deal with these challenges together as a couple, BA/BC men's preference for a solo approach amplified their preference to take personal responsibility for their CaP illness without 'sharing the burden' or exposing their vulnerability. Evidence suggests that perceptions of feeling insecure about their masculinity and a reluctance to share concerns with partners substantially contribute to a higher risk of mental health issues among men with CaP compared with those in the general population (Nanton *et al.* 2018).

The need to maintain a demeanour of strength in order not to increase anxiety in their partners may have further contributed to some men's reluctance to share their concerns with the women. Seminal literature on coping (Coyne *et al.* 1990) identified this behaviour as '*protective buffering*'⁸ which has been associated with elevated psychosocial distress among people living with chronic illnesses and their care-givers (Langer *et al.* 2009; Helgeson *et al.* 2017). Evidence highlights that adopting active engagement (Coyne *et al.* 1990) through open communications and shared problem-solving with their partners could help men deal with the psychological distress associated with feelings of lessened masculinity (Zaider *et al.* 2012) and also improve spousal adjustment to sexual dysfunction after CaP treatment (Galbraith *et al.* 2011).

5.2.3.4 Limited utilisation of external support

Intricate intersections between resilience, non-disclosure, gender and cultural beliefs further seemed to contribute to the reluctant attitude shown by many of the men in this study towards accessing of support groups or counselling services. Evidence on gender disparities in health behaviours shows that regardless of ethnic orientations, men generally record lower

utilisation of health and support services compared with women (Wang *et al.* 2013; Cleveland Clinic 2016; Schriver *et al.* 2017). Similar to findings in this study, previous studies (Rajbabu *et al.* 2007; Bastani *et al.* 2010; Memon *et al.* 2016) have also reported that some BME groups perceive attending counselling services as a sign of weakness or indicative of severe mental health problems (for example, madness which is a stigmatised health condition within BA/BC cultural settings). Such perceptions have been identified as barriers to access and utilisation of mental health services among BME groups (Memon *et al.* 2016). The reluctance shown by the majority of men in this study to engage in social support (for example, support groups) suggest that one-to-one peer support may be preferred by them. There were indications from study findings that men may feel more comfortable discussing their concerns with a colleague who had the same cultural values and similar disease experiences, without being stigmatised or being viewed as less resilient. Although there are suggestions from the literature that coping strategies such as open disclosure and accessing social support may reduce psychological distress among cancer patients (Williams *et al.* 2014), evidence from this study is not substantial enough to indicate whether men who disclosed their CaP or attended support groups coped better than those who did not.

As previously reported among Caucasian men with CaP (King *et al.* 2015), perceptions of healthcare experience varied among men in this study with the majority reporting more positive perceptions than negative. Positive perceptions of healthcare were mostly attributed to being offered information to alleviate men's concerns regarding cancer fatality and having empathetic doctors. These findings mirror reports from Black men in previous related studies (Gray *et al.* 2005; Bache *et al.* 2012). Although poorer experiences of healthcare have been reported among Black men (Pedersen *et al.* 2012), men's reports of having less expectations

from HCPs may have further contributed to positive perceptions of their healthcare experience in this study. Regardless of this, some men still reported negative healthcare experiences which were mostly attributed to subtle stereotypic behaviour (for example in language use) from HCPs and lack of recognition for their (men) psychosexual and psychosocial (information and communication) support needs. These findings are consistent with findings from other BA/BC men with CaP (Nanton and Dale 2011; Anderson *et al.* 2013).

Perceptions of cultural stereotyping by HCPs were not mutually shared by all the men in this study but the majority of them suggested the need for improved cultural sensitivity through ethnic matching of HCPs with patients. This suggestion should be acknowledged. However, it is also pertinent to recognise that apart from practical limitations in ethnic matching of HCPs with patients, this strategy could also potentially increase cultural stereotyping and discrimination in healthcare delivery rather than alleviate it, especially in a culturally diverse setting like the UK. Nevertheless, it is essential to increase the cultural awareness and competence of HCPs to enable them navigate ethnic barriers and deliver culturally sensitive support for men with CaP regardless of their ethnicity or cultural orientations. Further suggestions to improve cultural sensitivity and competence in healthcare delivery are highlighted in section 5.6.5.

5.2.4 Partner role and experiences

The peripheral role of partners along the CaP journey and the implications this had on their coping and support experiences have been fully discussed in **Paper 3** (see section 4.4 in Chapter Four).

5.2.5 Delineating cultural differences - healthcare professionals' perspectives

The task of delineating nuanced cultural differences between BA/BC and Caucasian patients in order to appropriately tailor psychosocial interventions, seems to be challenging given the gender specificity of CaP. Moreover, Caucasian men were not included in this study as a comparative group to differentiate such cultural differences. However, the inclusion of HCPs (who noted cultural disparities among their CaP patients through their first-hand experiences of caring for them during their disease journey) in this study may have made the task less challenging. Exploring the data from men's and partners' interviews from HCPs' perspectives and comparing with the literature on Caucasian groups may also have provided a stronger evidence to address this task. For example, HCPs' data validated men's and partners' narratives in this study and previous data on Caucasian groups (O'Callaghan *et al.* 2014; Pinder *et al.* 2016; Pinks *et al.* 2018) regarding disparities in partner involvement and role in men's CaP journey. As similarly evidenced in the men's and partners' data, the natural tendency for BA/BC men to take ownership and control of the CaP journey was also recognised by HCPs. These were mostly described in terms of the men controlling decisions regarding when to get treated for their CaP, preferring natural potency to using clinical aids and limiting the involvement of their partners in their healthcare appointments. All these were noted by the HCPs to be different from the pattern of behaviour observed among Caucasian patients.

Compared with the men themselves whose responses may have been biased by their singular cultural context (Bhopal 2006), HCPs' varied experiences of caring for both Black and Caucasian patients may have informed their differing perspective as highlighted above. Nevertheless, there is need to avoid stereotyping in HCPs' perceptions of BA/BC men's responses and behaviours towards CaP. For example, HCPs' perceptions that Black men's delay

in getting treated for CaP was mostly due to sexual concerns did not seem to take into account wider factors which may further contribute to such behaviour among this population. For example, the few men who reported delaying treatment in this study attributed their delays to use of traditional remedies and praying for divine healing. The immigrant status of BA/BC men (ONS 2015) also suggest that some of them may have families in their home countries to whom they have responsibilities. This may further impact on their delayed taking up of treatment for their CaP compared with indigenous Caucasian men. For example, the priority of a participant in this study was to travel to his home country to bury his mother before getting treated for his CaP. These bring to bear the complexity and multifaceted nature of different other factors (apart from sexual concerns) which may also influence the patterns of behaviour of BA/BC men towards CaP treatment.

On the other hand, men's descriptions of themselves as proactive help-seekers in this study may have been biased by the majority of them being well-educated and seemed positively disposed to information seeking (as reflected in their enthusiasm to participate in this research). However, increase in health promotion campaigns on the need for Black men to be aware of their higher risks of developing CaP (PCUK 2016), men being aware of a family history of breast/CaP cancer, and a resilient attitude could provide reasonable rationales for the men's self-reported promptness in taking up CaP treatment. Arguably, men's description of a proactive help-seeking behaviour may have conflicted with HCPs perspectives due to a subjective perception of their experiences as the help-seeker and also HCPs' perceptions of the men's experiences as the help-provider (Killam 2013). In order to enhance the ability of the newly introduced five-year strategic plan of the NHS (which includes improving physical and mental health experiences among people with cancer) (NHS England 2017b) to produce its desired results, it is essential to

synchronise the patient's actual experiences and needs with HCPs' perceptions through open patient-provider communication. This could potentially help to avoid assumptions of patient's experiences and needs, improve cultural sensitivity in healthcare delivery and also facilitate improved healthcare experiences for cancer patients.

5.3 Triangulation of the three data sets

In addition to triangulating the men's data with HCPs as highlighted earlier, their (men) narratives were also compared with partners' data and vice-versa. Whilst they validated some of each other's experiences, some disparities were observed especially regarding their recovery priorities and men's perceptions of their partners' needs. Disparities in recovery priorities have also been previously reported among African American couples where contrary to men's priority for sexual recovery, partners prioritised the men's total recovery from the CaP cancer (Rivers *et al.* 2011). For men in this study, it appeared their lack of recognition for partners' support needs may have been compounded by communication gaps in discussing concerns with each other and the woman controlling her emotions in order not to upset her husband. This suggests that engaging both the man and his partner as a unit when providing post-treatment support could be beneficial to help them understand their individual needs so they can support each other better. Triangulation of the three data sets was useful both to validate and also explore variations in their respective narratives to enhance the trustworthiness of the theory developed in this study.

5.4 ‘Man in the driving seat’: a substantive theory to understand the experiences of Black African/Black Caribbean men and their partners after prostate cancer treatment

Inductively developed from participants’ data, the emerged theory ‘man in the driving seat’ present an understanding of the patterns of behaviour of BA/BC men and their partners after CaP treatment within their cultural context. The theory suggests a hierarchical power structure in the marital (and also family) relationships within the BA/BC culture (Odimegwu and Somefun 2017) and this appeared to have been translated to the CaP experience especially with regards to decision-making, coping with treatment side effects, accessing support and perceptions of their priority needs. Comments by partners in this study that Black men do not like being told what to do have also been reported among AA groups (Sanchez *et al.* 2007; Owens *et al.* 2015) and validates this hierarchical power structure in BA/BC relationships. This may have contributed to partners’ accepting behaviour towards the men’ decisions (for example, regarding disclosure).

The influence of age on how men may enact the core values of their masculinity (mentioned earlier in Section 5.2.1) has also been recognised within the wider literature (Shim *et al.* 2015). The assumption is that younger men often exhibit greater self-independence compared with older men (Shim *et al.* 2015). Such an assumption coupled with perceptions that they were the ones directly affected by the physical symptoms of treatment side effects may have further contributed to the self-dependent and controlling behaviour reported by BA/BC men in this study towards treatment decisions and management of post-treatment side effects, as the majority were aged 65 years or less. Comparable findings from Nanton and Dale’s (2011) study also showed a similar trend among their younger BC participants who reported asking questions and seeking additional information before making treatment decisions. The older men (aged over 75 years) in

the study expressed an ‘accepting’ behaviour towards treatment recommendations from their doctors and found it difficult to voice their concerns even where they experienced difficulty in managing their post-treatment side effects (Nanton and Dale 2011).

The impact of treatment-induced sexual dysfunction on BA/BC men’s masculinity has been well reported (Nanton and Dale 2011; Anderson *et al.* 2013; Bamidele *et al.* 2017a). However, its implications on their sexuality (especially within their marital relationship) has remained underexplored. The majority of current evidence on Black male sexuality has predominantly focused on the subject of HIV/AIDs (Fields *et al.* 2015; Garcia *et al.* 2016; Mathews *et al.* 2016). ‘Man in the driving seat’ provides some useful insights in this regard within the context of CaP, as it highlights a power imbalance in the sexual relationship among BA/BC men and their partners.

Power imbalance in sexual relationship seemed to be reflected in participants’ (men and partners) narratives where the men exhibited dominant control over marital communications on sexual problems while partners appeared to exercise caution both in bringing up the conversations or trying to initiate sex. Common gender expectations for women to prioritise their care-giving roles over sexual gratification coupled with an awareness of the negative impact of sexual dysfunction on their husband’s self-esteem, may have further pushed partners in this study to the back passenger seat in this regard, making communications on the subject difficult. Some men’s admittance of not knowing how to approach such conversations suggests that regardless of being in the ‘driving seat’, they also have their vulnerabilities which should be recognised. The importance of providing psychosexual support focused on couples to help them navigate this challenging aspect of the CaP experience and improve their sexual health post-treatment without upsetting the power structure in their sexual relationships, cannot be undermined.

'Man in the driving seat' further seem to challenge common acculturation assumptions that interactions between different ethnic communities may expose their members to possible changes to their indigenous cultural stance (Gregg and Saha 2006). For example, despite the majority of the men having lived in the UK for decades and some men being in a long term (more than a decade) inter-ethnic marriage with a Caucasian wife, they seemed to tenaciously hold on to cultural definitions of their masculine role and identity. This suggests the need to consider the influence of culturally informed masculine values on couples' experiences when developing psychosocial support for them after CaP treatment. It is also worthy to note that men's renegotiation of their masculinity in the area of sexual function seemed to have been influenced by the disease experience itself rather their acculturation to a culturally different UK society.

5.4.1 Discussing the new substantive theory with relevant existing theories

In comparison to some relevant theories considered earlier in Chapter Two (see section 2.5), the substantive theory developed in this study seem to provide a bespoke understanding of the experiences of under-studied BA/BC populations within their specific cultural context after CaP treatment. As discussed earlier (section 2.5.2, Chapter Two), the HBM has been criticised for its lack of explicit consideration for the influence of cultural factors on individual's attitudes and behaviours towards health prevention programmes and services (Taitt 2015). 'Man in the driving seat' seems to address this limitation as it elucidates that regardless of being aware of the potential benefits of accessing external support to help deal with their treatment side effects, cultural beliefs and gender stereotypes substantially influenced the help-seeking behaviour of BA/BC men with CaP towards such tertiary prevention resource. The enactment of self-efficacy

(which is a construct of the HBM) by BA/BC men in this study also seems to contradict the HBM's postulation that self-efficacy could promote health behavioural changes if triggered by cues to action (for example, treatment side effects). It appears within the BA/BC context, men's interpretation of self-efficacy seemed to be synonymised with self-sufficiency and being in control without needing external help regardless of being challenged by inevitable side effects of CaP treatment. 'Man in the driving seat' suggests the men believed in their capacity to initiate personal coping strategies to deal with their treatment side effects and admittance of vulnerability or seeking external support was perceived as a sign of weakness.

'Man in the driving seat' validates the relevance of hegemonic masculinity theory to BA/BC men with CaP. Men's self-sufficient, controlling and stoic behaviour in this study, may have been further underpinned by constructions of masculine role and identity around hegemonic masculinity within their cultural setting. This seemed to highlight the relevance of hegemonic masculinity to BA/BC groups but also suggests that beyond such gender stereotype, there are wider factors (such as culture, age, physical side effects of CaP treatment) which intricately intersect to influence the patterns of behaviour of BA/BC men in relation to CaP. Surprisingly, there were no notable differences between the BA and BC men interviewed in this study as they mostly referred to themselves as Black men and it appeared they viewed their experiences from that broad cultural lens. Whilst existing evidence suggests that cultural differences may exist between members of the Black racial group (Livingston *et al.* 2013), it appears that BA and BC men's shared cultural beliefs regarding hegemonic masculinity may have contributed to their similar views regarding being in the 'driving seat'. In their theory 'cancer through Black eyes', Mulugeta *et al* (2017) also identified substantial similarities in the beliefs and attitudes of their BA and BC participants towards cancer in general. 'Man in the driving seat' suggests there are

substantial similarities in the attitudes and behaviours of BA/BC men towards post-treatment challenges of CaP and indicates that psychosocial interventions tailored for them as a group could potentially cater for their individual needs.

‘Man in the driving seat’ also supports the tenets of the coping theory (Lazarus and Folkman 1984) which highlight that an intricate intersection between an individual’s circumstances (for example, specific side effects of CaP treatment) and cultural context determines how they may cope with a chronic illness (such as CaP). Categorising men’s coping strategies as either positive or negative may have been difficult in this study as coping seemed to be subjective to the individual’s cognitive/behavioural preferences and their intended outcomes. For example, whilst non-disclosure may appear as negative because of its adverse consequence in truncating partners’ access to support, it seemed to be a positive coping strategy for the men as it alleviated their concerns about losing personal control over their information and avoiding stigma associated with living with a CaP illness. This trend further supports Lazarus and Folkman’s (1984) postulation that both the cognitive and behavioural aspects of coping may be fluid depending on an individual’s interpretation of reality as influenced by their perception of their concerns regarding their illness situation.

5.5 Implications for practice

Findings from this study highlight the need for HCPs to be cognisant of how complex intersections between socio-cultural constructions of gender, age and high risk of CaP may influence the experiences and support needs of BA/BC men with CaP and their partners. BA/BC men’s prioritisation of their reproductive and breadwinning roles coupled with their reluctance to disclose their CaP or access external support also indicate that their psychological burden after

CaP treatment may be more heightened compared with that of their Caucasian counterparts. The impact of this on partners' experiences also needs to be acknowledged.

Although BA/BC men may not spontaneously admit their need for help due to underlying masculinity ego, HCPs may need to explore their professional expertise to navigate gender and cultural barriers to support these men in a culturally sensitive way (Watts *et al.* 2014). The men's portrayal of resilience in the face of a challenging CaP illness should not be interpreted as being self-sufficient or not needing help. Rather, psychosocial interventions could be focused on providing relevant information to empower men to self-manage their post-treatment symptoms in an appropriate way. Men's priority for self-help also underscores the relevance of the new objective of NHS England to empower patients to actively manage their own health and care whilst being guided by professional support (NHS England 2017b). The theory 'man in the driving seat' provides a tailored template which could potentially facilitate the achievement of this priority within the BA/BC context. Disparities in couples' perceptions of their priority needs suggest the need to consider gender-culture interactions when developing psychosocial interventions for men with CaP and their partners. Specifically for this study, findings highlight the crucial role of HCPs in educating and encouraging BA/BC men to engage more with their partners through open marital communications and shared problem-solving for post-treatment sexual challenges.

The few participants who reported disclosing their CaP diagnosis within their religious setting mostly only disclosed to their pastor. Men's narrations on how their pastors educated them (men) to take up medical treatment for the CaP whilst they (pastors) provided spiritual support through prayers reiterate suggestions that delivering cancer education and support through religious leaders could be a useful health promotion strategy for Black populations

(Baruth *et al.* 2013). The common use of faith and prayer as coping strategies among Black men is also well acknowledged both in the current study and within the literature (Zhang *et al.* 2013; Rivas *et al.* 2016; Bamidele *et al.* 2017a). Hence, the potential benefit of incorporating prayer and personalised pastoral care as options within psychosocial support offered to BA/BC CaP survivors and their partners could be considered so that patients/couples who desire such could be signposted to these resources (Koffman *et al.* 2008; Koenig 2012).

Many of the men and partners in this study did not appear too enthusiastic about support delivery via online channels. This reluctance was mostly attributed to the sensitive nature of the CaP subject and reduced proficiency in computer skills. However, the increasing relevance of online support programmes (facilitated by technological advancements) to enable quicker access to healthcare and promote self-management of long term side effects of cancer treatment (NHS 2017b) cannot be ignored. The convenience, anonymity and flexibility which online support offers may have contributed to its increasing use among men with CaP (Wootten *et al.* 2015) and may potentially be appealing to BA/BC men if encouraged and delivered in a safe and controlled manner. There is currently a dearth of research which has explored the use of online support among Black men with CaP. Systematic reviews on self-management of diabetes (Majeed-Ariss *et al.* 2015) and eHealth weight management interventions (Bennett *et al.* 2014) among BME patients identified that Black populations may engage more with online interventions if delivered via mobile devices and also complemented with human support from HCPs.

The recognition shown by the HCPs interviewed in this study for the men's needs and how they should be addressed, amplifies their commitment to continue to deliver quality healthcare devoid of cultural barriers and stereotypes as recommended by NICE (NICE 2012). Findings from a recent UK-based study which investigated the experiences of specialist nurses

working within the uro-oncology multidisciplinary team (MDT) (Punshon *et al.* 2017) further highlight the need for pro-activeness in addressing patients' psychosocial needs after CaP treatment. Moreover, men's participation in this study and unreserved discussion of their issues with a female researcher suggests that gender-cultural barriers can be successfully navigated if done in a professional manner, working with the men as partners.

5.6 Recommendations to address the psychosocial needs of Black African/Black Caribbean men with prostate cancer and their partners

5.6.1 Recommendation one: modify the content and delivery of psychosexual support for the men and their partners

Men and partners in this study identified psychosexual support as their priority need. HCPs could leverage on the resilient behaviour of BA/BC men to promote self-help as an effective strategy to address the psychosexual needs of this population (Sharpley *et al.* 2014b). This could be achieved by complementing face-to-face support with online interventions. Although some men and partners were less enthusiastic about online intervention, educating them on its advantages as a convenient and flexible resource which can still help to maintain their privacy, could potentially make it more acceptable to this population. Such online support should also be developed to reflect the BA/BC context to enable the men and their partners to identify with and engage more. For example, using Black men/couples, simple and clear language, could help personalise online support for this population and potentially enhance their interest in this mode of support. For men and partners with limited computer skills, a detailed guidance on how to navigate the online space and access the intervention could also be useful for

them. Noting the increasing use of portable devices such as mobile phones to access the internet, mobile functions may also be activated on online interventions to make it more accessible and appealing to men and partners who prefer to use their phones than computers (Bennett *et al.* 2014). More importantly, online support should be complemented with additional modes of delivery involving human contact (for example, face-to-face and telephone) to improve sensitivity in dealing with a sensitive illness (Rukgasa and Canvin 2011; Szolnoki and Hoffmann 2013).

5.6.2 Recommendation two: tailor the content and presentation of information and other psychosocial support for the men and their partners both at the clinical and social support levels

Factual information and education aimed at problem-solving and self-management may be more beneficial and acceptable to BA/BC men with CaP than emotional-focused interventions. Specifically including images which depict younger Black males on pre and post-treatment information materials may also help alleviate men's psychological distress of being afflicted with an old man's illness. In addition to psychosexual support, it is also essential to identify ways of supporting BA/BC men who are unable to return to work (but have dependant family) without making them feel stigmatised or incompetent. For example, incorporating financial planning and advisory services into psychosocial support for Black men with CaP may be beneficial for this population. Physical activity programmes may also be included within psychosocial support to make it more robust and interesting for the men and their partners. The programmes of prostate cancer support groups should be re-evaluated to increase focus on self-empowerment through information exchange with less focus on emotional support. This may

make such groups appealing to more BA/BC men with CaP. Noting the strength of peer support to promote a balanced strategy to address both the cultural and gendered concerns of Black men (Watkins *et al.* 2018), a personal buddy initiative could be introduced within support groups as this could potentially improve the effectiveness of such groups in addressing the needs of BA/BC men with CaP.

5.6.3 Recommendation three: recognise partner's support needs and incorporate these within the psychosocial support agenda

Tailored information and support addressed specifically to partners could potentially provide reassurances for them to know that they are recognised and also supported as co-patients of the CaP illness. Including partners in the psychosocial support agenda for CaP patients could also help to improve marital communications and potentially help to sensitise men to their partners' needs and promote problem-solving together as a couple (Harden *et al.* 2009). Noting that some men may find it initially difficult to adjust from their usual 'solo' approach to shared problem-solving with their partners, HCPs need to explore their professional training and competence to provide guidance and support for couples in a non-critical and un-biased manner.

5.6.4 Recommendation four: increase education on prostate cancer within the Black African /Caribbean Community

Increasing education that treatment for CaP comes with inevitable side effects which affect most men regardless of their ethnicity, social status or age, could potentially encourage BA/BC men to talk more about their illness and embrace a more positive attitude towards accessing post-treatment support. This could potentially help to reduce cultural perceptions of

stigma, address religious-cultural myths regarding cancer fatality and improve men's attitude towards disclosure within these communities. Noting their influence on men's experiences along the CaP journey, religious leaders and peers who have had prior experience of CaP treatment could be engaged in the development and dissemination of local educational programmes within BA/BC communities.

5.6.5 Recommendation five: improve cultural sensitivity and competence in delivering psychosocial support

Current limitations in financial and manpower resources coupled with existing equality laws on employment and training within the NHS (The King's Fund 2017) indicate a potential difficulty in meeting men's recommendation of increasing consultation time, face-to-face support delivery and ethnic matching of their healthcare team. Nevertheless, the importance of rapport building to facilitate better patient-HCP communication cannot be overemphasised. Having the same HCP following up with a group of men along their continuum of care could potentially help to facilitate rapport building within limited resources. Insights from this study could also be complemented with ongoing training on cultural awareness and competence to enhance HCPs' (regardless of their ethnicity) ability to successfully engage with Black men with CaP and improve their satisfaction with their support care along the CaP trajectory (NICE 2012). Individualised patient-HCP communication could also potentially help to reduce subjective disparities in patients' actual and perceived needs and facilitate improved healthcare experiences (NICE 2012). This can be achieved by agreeing (through verbal discussions and written documents) a holistic care plan with the patient. This could help locate men at the centre of their care without underestimating the professional role of HCPs (NHS England 2017b).

5.7 Strengths and limitations of the study

5.7.1 Strengths

The strength of a grounded theory study can be assessed by its originality, significance, usefulness and relevance (Van de Ven 1989; Glaser and Strauss 2017).

Originality: This is the one of the first studies (to the best of the researcher's knowledge) to explore the unheard views of partners of BA/BC men with CaP and HCPs caring for men with CaP. Snowballing through research participants enhanced successful recruitment of partners into the study. Collaborating with clinicians also facilitated the recruitment of a more heterogeneous (especially regarding age and country of origin) sample of BA/BC men with CaP compared with previous studies on this group which have predominantly involved older Jamaican men (for example, Nanton and Dale 2011). Triangulated data from the multiple sample groups included in this study enhances current limited understanding of the experiences and psychosocial needs of BA/BC men and their partners after CaP treatment. A new substantive theory was also developed from this study.

Significance: Findings from this research and the theory developed have potentials for scalability and transferability to other settings with similar socio-cultural characteristics as men and partners in this study. Measures taken to help future researchers determine the potential transferability of this study to their context have been discussed in the methodology chapter (Chapter Three, section 3.4.2).

Usefulness: This study is useful by adding to the evidence base on the psychosocial aspects of CaP illness among a high risk but under-studied group. The substantive theory developed in this study also provides a bespoke conceptual framework which could potentially

be used to inform context specific psychosocial intervention for UK-based Black men with CaP and their partners.

Relevance: Using a metaphor to describe the theory developed in this study enhances its relevance as a practical concept that different stake holders (including lay research participants) may easily understand and relate to (Van de Ven 1989). Verbal feedback received from presenting the theory to stakeholders through conference presentations, seminars, non-scientific programmes, member checking with the men and discussions with health professionals also indicates the potential relevance of the theory and the study as a whole.

5.7.2 Limitations

Convenience sampling of the majority of the men through their HCPs may have biased the sample towards men who seemed positively inclined towards help-seeking and research participation. The majority of men and partners in the study being younger and well-educated also suggest that findings from this study may not be representative of other Black men and partners with different characteristics. Not all the men who participated in this study had their partners participating. Hence the experiences of such partners were not explored. Lack of same sex partners in the study also suggests that findings here may not be representative of the views of such partners. Efforts to recruit participants through prostate support groups and the wider community (for example, church) were not successful. Accessing some participants from such avenues may have yielded a different demographic of participants with different data.

Whilst couples were interviewed separately to facilitate openness and enable focus on their individual experiences, interviewing them together as a couple may have promoted more in-depth discussions to enhance the credibility of their narratives. The researcher's attribute as a

younger female may not have prevented men from participating in this study. However, it is possible this may have also contributed to their portrayal of strength and coping well with the CaP. The men may possibly have been more open in sharing their concerns and perceived vulnerabilities with a Black middle-aged male interviewer. HCPs' narratives regarding BA/BC men's delayed help-seeking for CaP diagnosis and treatment may also have been biased by existing stereotypes on the attitude of Black men towards CaP. Although evidence from the men mostly negated these narratives, evidence from previous research supporting these stereotypes validates the HCPs' narratives.

5.8 Contributions to knowledge

This study has made tangible contributions to knowledge through peer-reviewed publications (see publication list) and presentation of findings at local and international conferences. Other specific contributions of this study to knowledge are highlighted below.

Firstly, the study (to the best of the researcher's knowledge) is one of the first to explore the experiences of partners of BA/BC men with CaP and found that the majority of their experiences (for example, feelings of exclusion and isolation) imitate that of partners within Caucasian populations. However, partners of BA/BC men with CaP seem to have lesser support due to their husband's restraint on the CaP disclosure within their wider social network and a lack of recognition for their needs both by their husbands and HCPs. The study identified a need for partner-focused support and also an inclusive support which engages with couples to help improve marital communications and intimacy after CaP treatment.

Secondly, exploring HCPs' perspectives on the research phenomena may have helped to promote a better understanding of the cultural differences in BA/BC men's response to CaP. In

addition to validating existing literature on lower levels of access and utilisation of support services by Black men with CaP, HCPs' data further identified less partner engagement among this patient group compared with Caucasian men. These findings were also validated by men and partners' data in this study.

Thirdly, this study identified shared cultural values between BA and BC men with regards to their perceptions of masculinity and how this influenced coping and adaptation to CaP. Men's predominant use of the racial term Black to describe their ethnicity and situating their CaP beliefs and experiences within this context suggest the homogeneous aspects of the BA/BC culture may outweigh any subtle inter-cultural diversity which may exist between them when it comes to CaP illness. Hence, psychosocial interventions tailored for BA and BC men as a group could be relevant and useful to cater for their individual needs.

Cultural emphasis of masculinity around fatherhood and breadwinning also seemed more predominantly voiced as impacting on the psychosocial well-being of the men in this study possibly due to the majority of them aged below 65 years old and still in productive years both sexually, and in terms of work. Study findings also suggest that a hierarchical power structure in marital relationship among BA/BC men and their partners and masculinity constructions around leadership and responsibility, may have further contributed to the men's preference for a solo approach in dealing with their post-treatment sexual dysfunction.

Lastly, the substantive theory developed in this study identified the need to consider socio-cultural definitions of masculine roles and identities within the BA/BC context and how these influence the experiences and support needs of men and partners after CaP treatment.

5.9 Directions for future research

Larger studies are required to improve the generalisability of the developed theory to other BA/BC groups whose demographics (for example, gender and socio-economic status) may be different from that of the men and partners who participated in this study. Studies which include same sex partners of BA/BC men with CaP could also provide additional insights into how socio-cultural constructions of masculine roles and identities impact on the CaP experiences in this particular setting.

Noting men's and partners' narratives on the role of religious leaders in supporting them along the CaP journey, future studies could engage religious leaders themselves (as potential service providers) to explore their knowledge and perceptions of CaP and their own perceptions of their roles in delivering post-treatment support to CaP survivors and their partners. Research focused on leaders of cancer support groups could also help to better understand their perspectives on the challenges of engaging with BA/BC men with CaP and also clarify the specific roles of these organisations in supporting men and partners after CaP treatment. Such research studies which involve religious and support group leaders could provide additional useful insights to guide the content and delivery of post-treatment support for CaP survivors and their partners via these avenues.

The influence of generational effects (reported by length of stay in the UK) and/or socio-economic status (level of education, job type) on men's and partners' CaP experiences did not seem clear in this study. For example, reluctant attitude towards public disclosure of their CaP and support delivery via online channels reverberated across participants regardless of how long they had been resident in the UK or their socio-economic status. It appeared some of the variations observed in their data may have been influenced more by their age differences. There

is need for larger studies to investigate specific variables and help determine how much of the men's experiences and perceptions of their support needs can be attributed to generational effects, socio-economic status or age.

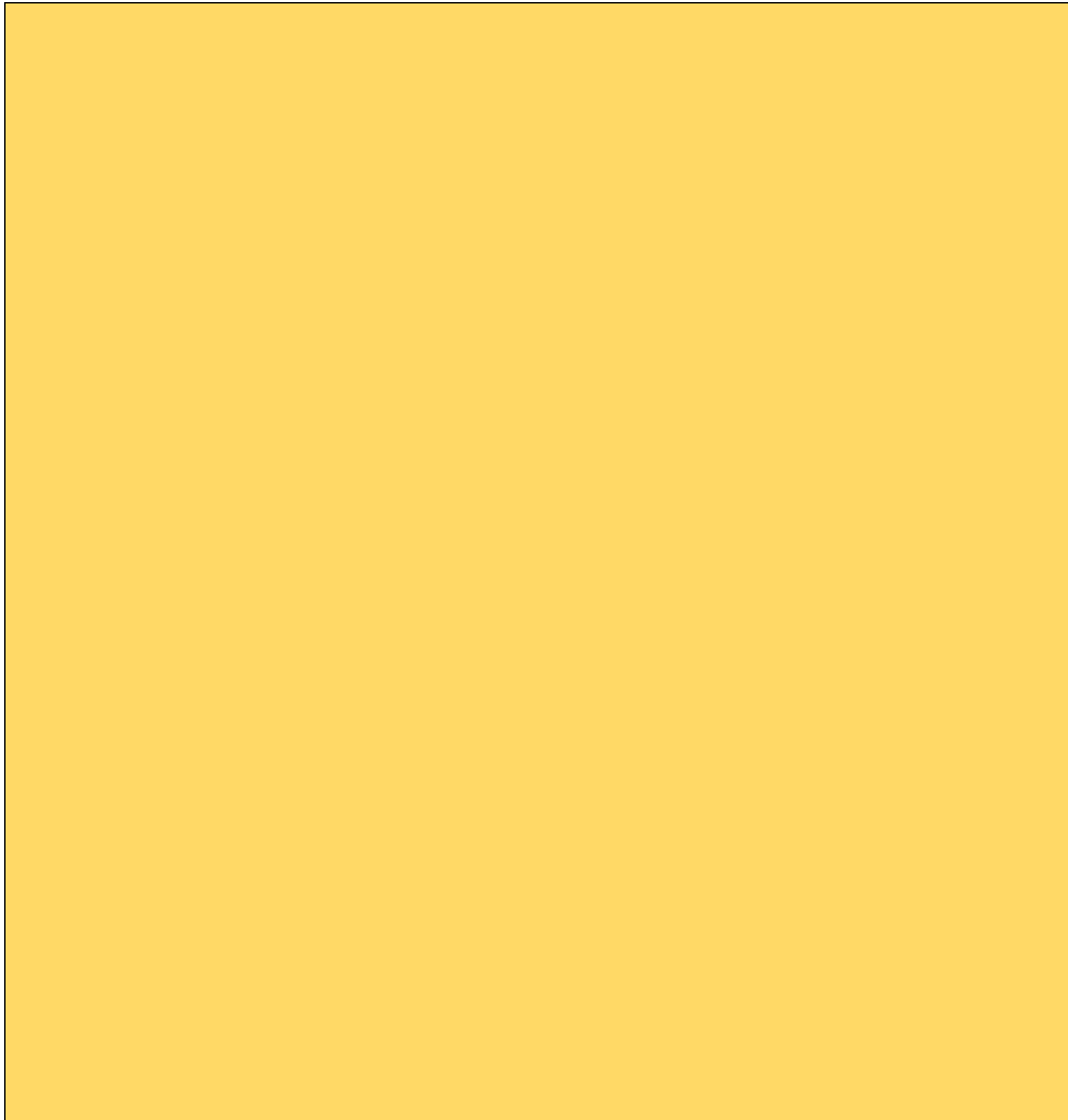
With the increasing relevance of digital healthcare, future studies could test the use and acceptability of online psychosocial support among BA/BC men with CaP and their partners. This could potentially help to develop more effective strategies to improve the engagement of these groups with online support resources.

6.0 Conclusions

The higher risk of developing CaP at a younger age and more aggressive form among BA and BC groups, long term impact of treatment side effects and a unique cultural context indicate that their post-treatment experiences and psychosocial support needs may be different from that of Caucasian groups. However, these phenomena were not well understood due to an underrepresentation of BA/BC groups in existing psychosocial research on CaP survivors. This study sought to address this gap by exploring in-depth, the experiences and psychosocial needs after CaP treatment for BA/BC men and their partners.

Findings suggest the post-treatment experiences of BA/BC men with CaP and their partners substantially reflect those of Caucasian groups. However, nuanced cultural differences existed in their responses and coping with the disease, which the theory 'man in the driving seat' may have helped to explicate. Regardless of these differences, the compulsion of CaP to challenge ingrained culturally informed masculinity beliefs suggests the need to acknowledge the intrinsic vulnerability of all individuals when faced with a life-threatening illness, regardless of their gender or its associated cultural stereotypes. BA/BC men and their partners' expressions of

frustration at the current lack of information and psychosexual support to help navigate challenging marital communications and deal with post-treatment side effects, supports previous evidence on Caucasian and AA groups. This study adds its voice to previous research on the need to increase psychosocial and psychosexual support for CaP survivors regardless of their ethnicity or cultural backgrounds. However, the content and delivery of such support should consider age disparities in CaP risk and occurrences, socio-cultural gender values and ethnic diversities in response and coping with CaP.



APPENDICES

Appendix 1: Telephone screening protocol

Men's eligibility will be assessed by asking the following questions;

1. How would you define your ethnicity? **Black African or Black Caribbean** (*proceed to question 2*). *If ethnicity is neither Black African nor Black Caribbean, thank the participant for their interest and explain that they are not eligible as only BA or BC men with prostate cancer will be involved in the study.*
2. What is your country of birth? (**Jamaica, Guyana, Barbados, West Indies, Trinidad and Tobago, Grenada and Barbuda, Nigeria, Ghana, Kenya, Zimbabwe, Malawi, Somalia, Zambia, Cameroun, Sierra Leone, Uganda**) (*If participant originates from any of the countries listed above, proceed to question 3. If does not originate from any of the countries listed above, confirm if country mentioned is in West/East Africa or the Caribbean and proceed to question 3. If country of birth is the UK or any other country, go to question 4*).
3. How long have you been resident in the UK? (*If relocated to the UK by self or brought to the UK by parents, go to question 5. If born in the UK or any other country, go to question 4*)
4. If country of birth is the UK or any other country, where are your parents originally from? (**Jamaica, Guyana, Barbados, West Indies, Trinidad and Tobago, Grenada and Barbuda, Nigeria, Ghana, Kenya, Zimbabwe, Malawi, Somalia, Zambia, Cameroun, Sierra Leone, Uganda**) (*If both parents originate from any of the countries listed above, proceed to question 5. If both parents do not originate from any of the countries listed above, confirm if country(ies) mentioned is/are in West/East Africa or the Caribbean and proceed to question 5. If not a West/East African or Caribbean country, thank participant for their interest and explain that they are not eligible because the research is targeted at 1st or 2nd generation Black African/Black Caribbean men with prostate cancer*)

5. Would you say you are first or second generation Black African or Black Caribbean?
(If answered Yes, proceed to question 6. If not sure, consider the answers earlier provided for questions 1-4 and proceed to question 6)
6. Have you already undergone treatment for prostate cancer at least three months previously? **Yes** *(proceed to question 7). No* *(thank the participant for their interest and tell them that unfortunately they are not eligible to participate in the research at this time. Explain to them that they must be at least three months' post treatment in order to give them time for immediate recovery and be able to identify their specific post treatment needs better. Also mention that when they are three months' post treatment and if still interested in participating in the research, they may contact the researcher to find out if recruitment is still on-going for the research)*
7. What treatment did you have for your prostate cancer? **Radiotherapy** *(proceed to question 9); Surgery* *(proceed to question 9); Hormone Therapy* *(go to question 8)*
8. If hormone therapy treatment, why? *(If indicative of palliative stage, thank the participant for their interest and explain that they are not eligible as their needs may be different from what will be investigated in this study. If no indication of palliative care, continue to question 9)*
9. What is the current stage your prostate cancer? *(If indicative of palliative stage, thank the participant and explain that they are not eligible as their needs may be different from what will be investigated in this study. If no indication of palliative care, continue to question 10)*
10. The participant information sheet and consent form are written in English. Are you able to read and understand English and sign a consent form by yourself? *(If yes, proceed to question 11. If No, thank the participant for their interest and explain that*

they are not eligible because they will be required to personally read and understand the participant information sheet in order for them to be able to provide written informed consent to participate in the research)

11. If you are to participate in the interview, would you require an interpreter? *(If answered Yes, thank participant for their interest and explain to them that they are not eligible as interpreters will not be allowed due to very personal questions which will be asked during the interviews. If answered No, inform participant that they are eligible to participate in the study and request for their contact details to send an information pack to them.)*

Partner's eligibility will be assessed by asking the following questions:

1. How would you define your partner's ethnicity? **Black African or Black Caribbean** *(proceed to question 2). If partner's ethnicity is neither Black African nor Black Caribbean, thank the participant for their interest and explain that they are not eligible as only partners of BA or BC men with prostate cancer will be involved in the study)*
2. Where is your partner's (or their parents') country of origin? **(Jamaica, Guyana, Barbados, West Indies, Trinidad and Tobago, Grenada and Barbuda, Nigeria, Ghana, Kenya, Zimbabwe, Malawi, Somalia, Zambia, Cameroun, Sierra Leone, Uganda)** *(If partner with prostate cancer (or his parents) originate from any of the countries listed above, proceed to question 3. If partner with prostate cancer (or his parents) do not originate from any of the countries listed above, confirm if country mentioned is in West/East Africa or the Caribbean and proceed to question 3. If partner was born in the UK or any other country but his parents originated from West/East African or Caribbean country, proceed to question 3. If partner was born in the UK or any other country and both parents do not originate from a West/East African or Caribbean country, thank participant for their interest and explain that they are not eligible because the research is targeted at partners of 1st or 2nd generation Black African/Black Caribbean men with prostate cancer)*
3. Has your partner already undergone treatment for prostate cancer at least three months previously? **Yes** *(proceed to question 4). No* *(thank the participant for their interest*

and tell them that unfortunately they are not eligible to participate in the research at this time. Explain to them that their partner must be at least three months' post treatment in order to give them time for immediate recovery and be able to identify their specific post treatment needs better. Also mention that when their partner is three months' post treatment for his prostate cancer and if they are still interested in participating in the research, they may contact the researcher to find out if recruitment is still on-going for the research)

4. What treatment did your partner have for his prostate cancer? **Radiotherapy** (*proceed to question 6*); **Surgery** (*proceed to question 6*); **Hormone Therapy** (*go to question 5*).
5. If hormone therapy treatment, why? (*If indicative of partner on palliative care, thank the participant for their interest and explain that they are not eligible as their needs may be different from what will be investigated in this study. If no indication of partner on palliative stage, continue to question 6*)
6. What is the current stage your partner's prostate cancer? (*If indicative of palliative stage, thank the participant and explain that they are not eligible as their needs may be different from what will be investigated in this study. If no indication of palliative stage, continue to question 7*)
7. Are you aged 18 years and above? (*If yes, proceed to question 8. If No, thank participant for their interest and explain that they are not eligible as they are below the legal age limit required to provide consent to participate in the research*)
8. The participant information sheet and consent form are written in English. Are you able to read and understand English and sign a consent form by yourself?? (*If yes, proceed to question 9. If No, thank the participant for their interest and explain that they are not eligible because they will be required to personally read and understand the participant information sheet in order for them to be able to provide written informed consent to participate in the research*)
9. If you are to participate in the interview, would you require an interpreter? (*If answered Yes, thank participant for their interest and explain to them that they are not eligible as interpreters will not be allowed due to very personal questions which will be asked during the interviews. If answered No, inform participant that they are eligible to participate in the study and request for their contact details to send an information pack to them.*)

Appendix 2: Research participation letter



Dear

Re: Research Participation to Explore the Psychosocial Needs after Prostate Cancer Treatment for Black African and Black Caribbean Men and Partners in the UK

Thank you for expressing an interest to participate in the above study. As discussed, please see attached a participant information sheet containing detailed information regarding the purpose of the study and what your participation would involve.

Kindly read through the information sheet and if you are happy to proceed with your participation, please sign the attached consent form and return within 2 weeks of receiving this pack, to myself at the address below. You can send your signed consent form either by post using the pre-stamped addressed envelope or by email (please see below).

Once I receive your signed consent form, I will contact you again to arrange a time and venue that is convenient for you for the interview.

I look forward to hearing from you again soon. If there are any questions about any aspect of the study, please do not hesitate to contact me.

Yours sincerely,

Olufikayo Bamidele (PhD Student)
Room 12J06, School of Nursing
Ulster University, Jordanstown Campus
Newtownabbey
N Ireland BT37 0QB
Tel: 07405737641
Email: Bamidele-O@email.ulster.ac.uk

Appendix 3: Sample Participant Information Sheet

approximately between 60mins – 90mins. We may ask you to take part in a shorter follow-up interview at a later date to elaborate more on some of the information from the previous interview. As this research is also aimed at identifying the specific needs of partners, if you have a partner and you do not mind, please could you also let your partner know about the study. If your partner expresses an interest, please ask them to contact me and I will forward them further information. We will like to interview you and your partner (if applicable) separately but if you wish to be interviewed together with your partner (if applicable) this can be arranged. You are still eligible to participate in this research even if your partner does not wish to participate.

Do I have to take part in the research?

No, you do not have to take part if you do not wish to. Participation in this study is completely voluntary. It is up to you to decide whether or not you want to take part. If you decide to take part, you will be requested to sign the enclosed consent form and return it to myself using the enclosed pre-stamped envelope within 2 weeks of receiving this information pack. If necessary and if you decide to participate in a second interview, you will also be requested to sign a second consent form following the same procedure. Even after signing the consent form you are free to withdraw from the study or choose which questions you want to answer and those that you do not. If you do decide to withdraw after the interview has commenced you do not have to give a reason, we would ask for your consent to be able to use all data collected up to the point. If you decide not to participate, your decision will still be respected. Your participation or non-participation will not affect your healthcare in anyway as this is an independent study.

Will my information be kept confidential?

Yes. All information you share during the interviews will be treated in the strictest confidence and none of your details will be shared with anyone other than members of the research team. Your information will be anonymised and securely kept in lockable drawers and on password-protected computer with access restricted to the research team only. All information will be handled and stored in accordance with the requirements of the Data Protection Act 1998 and will be destroyed after ten years in line with our University policy. If you disclose any psychological or emotional concerns during the interview the interview will be stopped and will only continue when and if you are happy to proceed. If required, you will be sign-posted to available counselling services and advised to speak to your main healthcare provider.

What will happen to the results of the research study?

It is anticipated that the information from the interviews will provide evidence to help inform the provision of appropriate support care to address the psychosocial needs of Black African and Caribbean men and their partners after prostate cancer treatment. Once complete, the study findings will be published in scientific journals, on relevant support/participating organisation's website and presented at conferences. You may request to receive a written summary of the key findings from the study and an opportunity to discuss this with the research team if you wish.

Who is organising and funding the research?

This study is being led and fully funded by Ulster University, Northern Ireland.

Who has reviewed/approved the study?

The study has been reviewed and approved by the Ulster University Research Ethics Committee, Health Research Authority (HRA), Barts Health Trust, Guy's and St Thomas's Trust and Royal Marsden Trust.

What happens if something goes wrong?

This research has received ethical approval from Ulster University, Health Research Authority and research governance from NHS Trusts. It is very unlikely that anything will go wrong. Ulster University has procedures in place for reporting, investigating, recording and handling adverse events. Further details of the University's complaints procedure can be found at:

https://www.ulster.ac.uk/data/assets/pdf_file/0011/75638/Complaints.pdf If you wish to make a complaint, you can also either contact the chief investigator (Professor Eilis McCaughan, please see contact details below), and she will try to answer your questions. If you still remain unhappy and wish to complain formally please contact Mr Nick Curry, Senior Administrative Officer, Research & Innovation, Ulster University, Jordanstown campus, Shore Road, Newtownabbey, Co. Antrim, BT37 0QB. TEL: +44 28 90366629; EMAIL: n.curry@ulster.ac.uk

Further information and contact details

If you have any queries or would like further information on the study, please feel free to contact a member of the research team. Contact details are provided below:

Mrs. Olufikayo Bamidele (PhD Student)
Institute of Nursing and Health Research
Ulster University
Jordanstown, Co Antrim
Northern Ireland
BT37 0QB
Tel: 07405737641
Email: Bamidele-O@email.ulster.ac.uk

OR

Prof Eilis McCaughan (Chief Investigator)
Professor in Cancer Care
Institute of Nursing and Health Research
Ulster University
Coleraine, Co Derry Northern Ireland
BT52 1SA
Tel: 028 70124091;
Email: em.mccaughan@ulster.ac.uk

Appendix 4: Consent form



Title of Study: *Post Treatment for Prostate Cancer: The Psychosocial Needs of Black African and Caribbean Men and their Partners*

Participant Number:

Name of Researchers: Mrs Olufikayo Bamidele (PhD Student)
Prof Eilis McCaughan (Chief Investigator)

Please
initial each
box

I confirm that I have understood the information sheet provided by the researchers for the above study and have had the opportunity to ask questions and have had any questions answered to my satisfaction.

☐

I understand that my participation is voluntary and that I am free to withdraw at any time and that I can refuse to answer questions without giving any reason and without my healthcare being affected.

☐

I agree to the interview being tape recorded and understand all quotes used will be anonymised

☐

I agree that if I do not wish to continue with the interview either due to distress or any other reason, the data collected up to that point can be used for the purpose of the research

☐

I agree to take part in the above study

☐

I understand that relevant sections of my medical notes and data collected during the study, may be looked at by individuals from Ulster University, from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records

☐

Name of Participant

Signature

Date

Name of Person taking consent

Signature

Date

Appendix 5: Topic guides for interviews with the men



Initial Topic Guide – Men

Post Treatment for Prostate Cancer: The Psychosocial Needs of Black African and Caribbean Men and their Partners

INTRODUCTION

- Welcome participant and introduce self.
- Confirm with participant they have had chance to read participant information sheet and aware of purpose of interview
- Explain format of the interview
- Explain consent procedure, the presence/purpose of an audio-recorder and double-check consent form has been signed
- Address the issue of confidentiality.
- Explain that participation is voluntary and that participation can be stopped at any time.
- Any questions before we start?

PROPOSED INTERVIEW QUESTIONS:

The following topics will be used to open up discussions in line with study objectives. Participants will be allowed to lead the discussion whilst the researcher uses relevant prompts where necessary.

Objective 1: To investigate the experiences of BA and BC men with CaP; and where applicable also the experiences of their partners respectively.

1. Experience of treatment received since diagnosis
2. Impact of treatment experiences on personal perception of masculinity
3. Impact of diagnosis and treatment on sexual health and intimacy
4. Cultural beliefs and attitude regarding prostate cancer and its influence on coping with treatment experiences

Objective 2: To examine men and partners' respective perceptions of support care after CaP treatment

5. Support care/service accessed post-treatment – previous/current
6. Explore delivery of previous and current support care/serviceProbe Type/format? When? By whom?

Objective 3: To investigate from men and partner's perspectives, what are their perceived individual needs and the needs of each other post-treatment for CaP

7. Priority need for self as someone who had been treated for prostate cancer
8. Priority need for partner

Objective 4: To examine suggestions for interventions that could address the needs of BA and BC men with CaP and their partners

9. Preferred support care/service Probe: Type of support / format support/mode of delivery?
10. Improvement of current support care/service Probe: Type/format of intervention?
When? By whom? Mode of delivery?

Demographic data

So that I have an overview of the demographic/background to those that participated in the study I would like to ask a few questions about yourself. If there are any questions you do not wish to answer, please just say and I will move onto the next:

- Age
- Nationality/Place of birth (*in Africa, the Caribbean*)
- Marital status (*married, single, number of children etc.*)
- Educational/employment background (*level of education, type of job*)
- How long have you been resident in the UK?
- When you were first diagnosed with prostate cancer?
- What type of treatment have you had for your prostate cancer?

CLOSING

- Member checking (to check researcher's understanding/interpretation with the participant of what they have said)
- Thank the participant, re-emphasise confidentiality and confirm if happy to be contacted for a second interview if necessary.
- Inform participant that findings from the study will be available October 2018 and they can have a copy of the study findings on request by emailing the Chief Investigator (Professor Eilis McCaughan).

Modified Topic Guide 1 – Men

- Tell me about your prostate cancer experience
- Explore psychological, emotional, and social impact – what contributes to these??-
- How do the treatment side effects affect your daily life? Work life, social life, marital life/– changes? Thoughts and feeling regarding changes made?
- Within your cultural context, tell me about how your treatment has impacted on you and your marital relationship. –sexual relationship, intimacy, communication etc.
- How maintaining intimacy with partner at this time?
- From a Black man’s perspective, what is the cultural implication of having prostate cancer?
- Explore coping mechanisms
- Personal perception of self after treatment – explore masculinity ideals within their socio-cultural context
- Explore information-seeking – online, peers, HCPs, other sources? Appropriate ways of targeting such information and what content of such information should be?
- Explore healthcare experiences
- Explore what is culturally sensitive healthcare?
- Support experience post-treatment
- Explore psychosocial/psychosexual support experience - as individual? As a couple?
- Perceptions of support experience
- How does sexual dysfunction impact on you as a Black Man?
- How did you handle it?
- What other support would you recommend?
- How would you like such support to be delivered?
- How do you think your partner has been impacted by your prostate cancer?
- What are your priority needs at this stage of your prostate cancer journey? Why?
- How do you feel about your needs?
- How do you think your needs can be best addressed?
- What do you think are your partner’s priority needs? Why?
- How do you feel about your partner’s needs?
- How do you think your partner’s needs can be best addressed?
- Is there anything else you will like to tell me?
- Demographic information
 - Age
 - Country of origin
 - Marital Status
 - How long since married/been with partner
 - Highest Educational Qualification
 - Employment status/Job type
 - How long since resident in the UK
 - How long since diagnosed with prostate cancer
 - How long since treated for prostate cancer
 - Treatment type received
- Thank participant and re-emphasise confidentiality

Modified Topic Guide 2 – Men

- What does it mean to be ‘in control’? Cultural dictates? Personal reasons? Societal expectations?
- Explore resilience?
- Why limited involvement of partner in decision-making, communication?
- Explore marital communications and decision-making process in cultural context
- Explore personal perceptions regarding disclosure
- Explore issue of stigma in relation to disclosure?
- Explore peer support- what does it mean? Why is it preferred?
- How do you feel about your partner’s needs?
- Explore how engaging with partner to manage treatment side effects?
- What can be done to help men and partners communicate better?
- How can healthcare professionals engage partners without breaching cultural values and beliefs?
- What are your priority needs at this stage of your prostate cancer journey? Why?
- How do you feel about your needs?
- How do you think your needs can be best addressed?
- Explore use of support group in face to face setting, what will you like to discuss? How often? What location? Will you attend? Time duration?
- What are your thoughts regarding support delivered via online channels?
- Is there anything else you will like to tell me?
- Demographic information
- Thank participant and re-emphasise confidentiality

Appendix 6: Topic guides for interviews with the partners



Initial Topic Guide – Partner

Post Treatment for Prostate Cancer: The Psychosocial Needs of Black African and Caribbean Men and their Partners

INTRODUCTION

- Welcome participant and introduce self.
- Confirm with participant they have had chance to read participant information sheet and aware of purpose of interview
- Explain format of the interview
- Explain consent procedure, the presence/purpose of an audio-recorder and double-check consent form has been signed
- Address the issue of confidentiality.
- Explain that participation is voluntary and that participation can be stopped at any time.
- Any questions before we start?

PROPOSED INTERVIEW QUESTIONS:

The following topics will be used to open up discussions in line with study objectives. Participants will be allowed to lead the discussion whilst the researcher uses relevant prompts where necessary.

Objective 1: To investigate the experiences of BA and BC men with CaP; and where applicable also the experiences of their partners respectively.

1. Experience of being a partner to someone who had been diagnosed and treated for prostate cancer
2. Impact of partner's prostate cancer treatment on daily life and relationship
3. Impact of partner's prostate cancer treatment on sexual health and intimacy.
4. Cultural beliefs and attitude towards prostate cancer and how it has influenced coping with partner's treatment

Objective 2: To examine men and partners' respective perceptions of support care after CaP treatment

5. Support care/service accessed since partner's treatment for prostate cancer – previous/current
6. Explore delivery of previous/current support care/service accessed since partner's treatment for prostate cancer - Probe Type/format? When? By whom?

Objective 3: To investigate from men and partner's perspectives, what are their perceived individual needs and the needs of each other post-treatment for CaP

7. Priority need for self as partner to someone who had been treated for prostate cancer

8. Priority need for partner with prostate cancer

Objective 4: To examine suggestions for interventions that could address the needs of BA and BC men with CaP and their partners

8. Preferred support care/service Probe: Type of support / format support/mode of delivery?
9. Improvement of current support care/service Probe: Type/format of intervention? When? By whom? Mode of delivery?

Demographic data

So that I have an overview of the demographic/background to those that participated in the study I would like to ask a few questions about yourself. If there are any questions you do not wish to answer, please just say and I will move onto the next:

- Age
- Nationality/Place of birth (*Africa, the Caribbean, UK, other country?*)
- Educational/employment background (*level of education, type of job*)
- How long you have been in relationship with your partner?
- How long since your partner has been diagnosed/treated for prostate cancer?
- What type of treatment did your partner have for his prostate cancer?

CLOSING

- Member checking (to check researcher's understanding/interpretation with the participant of what they have said)
- Thank the participant, re-emphasise confidentiality and confirm if happy to be contacted for a second interview if necessary.
- Inform participant that findings from the study will be available October 2018 and they can have a copy of the study findings on request by emailing the Chief Investigator (Professor Eilis McCaughan).

Modified topic guide 1 - partner

- Tell me about your experience of being a partner to someone diagnosed and treated for prostate cancer
- Explore psychological, emotional, and social impact?
- Explore impact of prostate cancer on marital intimacy
- Explore cultural implications of husband's prostate cancer within their and husband's (if different) cultural contexts
- What is/are the most challenging aspect for you, of your partner's prostate cancer?
- Why is that the most challenging?
- How does that make you feel?
- Explore personal coping strategies
- Tell me about your support experience- sources? Type? Perceptions? Gaps?
- Any psychosocial or psychosexual support for partners or as a couple?
- Did you seek any psychosocial support? For example, group, online, individuals

- Perceptions of support experience for self
- What other support would you recommend?
- How would you like such support to be delivered?
- Explore information provision for partners
- Impact of partner's treatment on your family life, social life, work life etc.
- Demographic information
 - Age
 - Country of origin
 - Marital status
 - How long since married/been with partner with prostate cancer
 - How long since resident in the UK
 - Highest educational qualification
 - Employment status/job type
 - Length of time since partner diagnosed with prostate cancer
 - Length of time since partner treated for prostate cancer
 - Treatment type partner had for his prostate cancer
- Thank participant and re-emphasise confidentiality

Modified topic guide 2 - partners

- Probe disclosure – who? When? How? Why? Children, other family members etc.?
- Probe why partner was reluctant to disclose?
- Impact of limited disclosure of the CaP on support experience for self as partner
- Explore marital communication in relation to treatment decision-making and dealing with treatment side effect
- Explore marital communications and decision-making process in cultural context
- Probe suggestion on improving marital communications
- How do you feel about partner's sexual problems after treatment?
- Explore use of support group in face to face setting, what will you like to discuss? How often? What location? Will you attend? Time duration?
- What are your thoughts regarding support delivered via online channels?
- What are your expectations from healthcare professionals re supporting partners of men with prostate cancer?
- What are your priority needs now? Why?
- How do you think your needs can be best addressed?
- What do you think are your partner's priority needs now?
- How do you think your partner's needs can be best addressed?
- Is there anything else you will like to tell me?
- Demographic information
- Thank participant and re-emphasise confidentiality

Appendix 7: Topic guides for interviews with healthcare professionals



Initial Topic Guide – HCPs

Post Treatment for Prostate Cancer: The Psychosocial Needs of Black African and Caribbean Men and their Partners

INTRODUCTION

- Welcome participant and introduce self.
- Confirm with participant they have had chance to read participant information sheet and aware of purpose of interview
- Explain format of the interview
- Explain consent procedure, the presence/purpose of an audio-recorder and double-check consent form has been signed
- Address the issue of confidentiality.
- Explain that participation is voluntary and that participation can be stopped at any time.
- Any questions before we start?

Demographic data

So that I have an overview of the demographic/background to those that participated in the study I would like to ask a few questions about yourself. If there are any questions you do not wish to answer, please just say and I will move onto the next:

- Is English your first Language?
- Job title?
- Qualification?
- No of years qualified?
- Length of time working with patients with prostate cancer?
- Age?

PROPOSED INTERVIEW QUESTIONS:

The following topics will be used to open up discussions in line with study objectives. Participants will be allowed to lead the discussion whilst the researcher uses relevant prompts where necessary.

Objective IV: To investigate what health professionals perceive as the needs for BA and BC men post-treatment for CaP

1. Experience of providing care for BA and BC men with CaP
2. Communication in delivery of post-treatment support care for BA and BC men with CaP
3. Perception of BA and BC men's unique needs after CaP treatment

Objective v: To examine suggestions for interventions that could address the needs of BA and BC men with CaP and their partners

4. Probe: Type/format of intervention? When? By whom? Mode of delivery?

CLOSING

- Member checking (to check researcher's understanding/interpretation with the participant of what they have said)
- Thank the participant and re-emphasise confidentiality.
- Inform participant that findings from the study will be available October 2018 and they can have a copy of the study findings on request by emailing the Chief Investigator (Professor Eilis McCaughan).

Modified topic guide for HCPs

- Do you think there are any cultural differences between BA/BC and Caucasian patients with regards to the CaP? Probe what the differences are? And what informed HCPs' perceptions of such differences? Why?
- Explore communication in delivery of post-treatment care for BA/BC men with CaP- probe treatment decision-making? Dealing with side effects?
- Information provision for BA and BC men with CaP. Probe content? At what stage (s), Mode of delivery? Language use?
- Possible reasons why disparity in perceptions of healthcare experience among BA/BC patients attending same healthcare facility, cared for by same staff etc.
- Explore HCPs' perceptions of BA and BC men's unique needs after CaP treatment
- Current support provided for Black men after CaP treatment
- Explore how much partners are engaged in the healthcare process?
- Any support currently focused for partners or couples as a unit? What? How?
- Suggestions on how best to address Black men's need after CaP treatment. Probe: Type/format of intervention? When? By whom? Mode of delivery?
- Suggestions on how best to support partners after their partner's CaP. Probe: Type/format of intervention? When? By whom? Mode of delivery?
- Demographic details

Appendix 8: Ethical approval letter from Ulster University Research Ethics Committee (UREC)



Duplicate

Ulster University
Shore Road
Newtownabbey
County Antrim
BT37 4QB
Northern Ireland
T: +44 (0)28 3026 0332/01140607
info@ulster.ac.uk

Our Ref: NC:GDV

21 September 2018

Professor E McCaughan
Room H249
School of Nursing
Ulster University
Coleraine Campus

Dear Professor McCaughan

Research Ethics Committee Application Number: REC/16/0079

Study Title: Post treatment for prostate cancer: The psychosocial needs of black african and caribbean men and their partners

Thank you for your recent response to matters raised by the committee. This has been considered and the decision of the committee is that the research should proceed.

Please also note the additional documentation relating to research governance and indemnity matters, including the requirements placed upon you as Chief Investigator.

The committee's decision is valid for a period of three years from today's date (this means that the study should be completed by that date). If you require this period to be extended, please contact the Research Governance section.

1. Please complete and return the Chief Investigator Statement of Compliance prior to commencing the study and keep a copy for your file.
2. Please retain all other documents.

Further details of the University's policy along with guidance notes, procedures, terms of reference and forms are available on the Ulster University Portal.

If you need any further information or clarification of any points, please do not hesitate to contact me.

Yours sincerely



Nick Curry
Senior Administrative Officer
Research Governance
028 3026 0029
n.curry@ulster.ac.uk



Appendix 9: Ethical approval letter from the Health Research Authority (HRA) Ethical approval



Mrs Olufikayo Bamidele
Room 12J07, Institute of Nursing and Health Research
Ulster University
Jordanstown
BT37 0QB

Email: hra.approval@nhs.net

23 March 2017

Dear Mrs Bamidele

Letter of HRA Approval

Study title:	Post Treatment for Prostate Cancer: The Psychosocial Needs of Black African and Black Caribbean Men and their Partners
IRAS project ID:	216614
Protocol number:	16/0113
REC reference:	17/YH/0027
Sponsor	Ulster University

I am pleased to confirm that HRA Approval has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications noted in this letter.

Participation of NHS Organisations In England

The sponsor should now provide a copy of this letter to all participating NHS organisations in England.

Appendix B provides important information for sponsors and participating NHS organisations in England for arranging and confirming capacity and capability. Please read Appendix B carefully, in particular the following sections:

- *Participating NHS organisations in England* – this clarifies the types of participating organisations in the study and whether or not all organisations will be undertaking the same activities
- *Confirmation of capacity and capability* - this confirms whether or not each type of participating NHS organisation in England is expected to give formal confirmation of capacity and capability. Where formal confirmation is not expected, the section also provides details on the time limit given to participating organisations to opt out of the study, or request additional time, before their participation is assumed.
- *Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria)* - this provides detail on the form of agreement to be used in the study to confirm capacity and capability, where applicable.

Further information on funding, HR processes, and compliance with HRA criteria and standards is also provided.

It is critical that you involve both the research management function (e.g. R&D office) supporting each organisation and the local research team (where there is one) in setting up your study. Contact details and further information about working with the research management function for each organisation can be accessed from www.hra.nhs.uk/hra-approval.

Appendices

The HRA Approval letter contains the following appendices:

- A – List of documents reviewed during HRA assessment
- B – Summary of HRA assessment

After HRA Approval

The document *'After Ethical Review – guidance for sponsors and investigators'*, issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

- Registration of research
- Notifying amendments
- Notifying the end of the study

The HRA website also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures.

In addition to the guidance in the above, please note the following:

- HRA Approval applies for the duration of your REC favourable opinion, unless otherwise notified in writing by the HRA.
- Substantial amendments should be submitted directly to the Research Ethics Committee, as detailed in the *After Ethical Review* document. Non-substantial amendments should be submitted for review by the HRA using the form provided on the [HRA website](http://www.hra.nhs.uk), and emailed to hra.amendments@nhs.net.
- The HRA will categorise amendments (substantial and non-substantial) and issue confirmation of continued HRA Approval. Further details can be found on the [HRA website](http://www.hra.nhs.uk).

Scope

HRA Approval provides an approval for research involving patients or staff in NHS organisations in England.

If your study involves NHS organisations in other countries in the UK, please contact the relevant national coordinating functions for support and advice. Further information can be found at <http://www.hra.nhs.uk/resources/applying-for-reviews/nhs-hsc-rt-review>.

If there are participating non-NHS organisations, local agreement should be obtained in accordance with the procedures of the local participating non-NHS organisation.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application

IRAS project ID	216614
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procedure. If you wish to make your views known please use the feedback form available on the HRA website: <http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/>.

HRA Training

We are pleased to welcome researchers and research management staff at our training days – see details at <http://www.hra.nhs.uk/hra-training/>

Your IRAS project ID is 216614. Please quote this on all correspondence.

Yours sincerely

Beverley Mashegede
Assessor

Email: hra.approval@nhs.net

Copy to: Mr Nick Curry, Sponsor Contact
Elizabeth Clough, Lead NHS R&D Contact
Professor Ellis McCaughan, Chief Investigator

Appendix 10: Ethical approval letters from participating NHS Trusts

Mon 03/04, 18:15

Download Save to OneDrive - Ulster University

Dear Sponsor Representative,

RE: IRAS: 216614- Confirmation of Capacity and Capability at BARTS HEALTH NHS TRUST

Full Study Title:	Post Treatment for Prostate Cancer: The Psychosocial Needs of Black African and Black Caribbean Men and their Partners
Site PI/LC	Dr Frank Chinegwundoh
Protocol version:	Version 3 dated 28/2/2017
Latest HRA Approval date:	23/3/2017

This email confirms that **Barts Health NHS Trust** has the capacity and capability to deliver the above referenced study. Please find attached Statement of Activities as confirmation.

Barts Health NHS Trust agrees to start this study on a date to be agreed when you as sponsor give the green light to begin. Please ensure the R&D office and local CRN contacts are provided with this date.

If you wish to discuss further, please do not hesitate to contact JUMO and local Trust R&D team (cc-ed above).

Please note, in line with the national HRA approvals process, you will no longer receive a NHS R&D Approval/Permission letter.

Kind Regards

Research Governance Team Leader

The Joint Research Management Office
Queen Mary Innovation Centre

1 of 20

Olufikayo Bamidele
2 Clontarf Manor
Newcastle
Northern Ireland

Our ref: LOA 768

Date: 19/06/2017

Dear Olufikayo,

Letter of access for: Post Treatment for Prostate Cancer: The Psychosocial Needs of Black African and Black Caribbean Men and their Partners

R&D Reference: 216614

REC Reference: 17/YH/0027

This letter confirms your right of access to conduct research through Guy's and St Thomas's NHS Foundation Trust for the purpose and on the terms and conditions set out below. This right of access commences on the **19/06/2017** and ends on the **01/10/2018** unless terminated earlier in accordance with the clauses below.

You have a right of access to conduct such research as confirmed in writing in the letter of permission for research from this NHS organisation. Please note that you cannot start the research until the Principal Investigator for the research project has received a letter from us giving permission to conduct the project.

The information supplied about your role in research at Guy's and St Thomas's NHS Foundation Trust has been reviewed and you do not require an honorary research contract with this NHS organisation. We are satisfied that such pre-engagement checks as we consider necessary have been carried out.

You are considered to be a legal visitor to Guy's and St Thomas's NHS Foundation Trust premises. You are not entitled to any form of payment or access to other benefits provided by this NHS organisation to employees and this letter does not give rise to any other relationship between you and this NHS organisation, in particular that of an employee.

While undertaking research through Guy's and St Thomas's NHS Foundation Trust you will remain accountable to Ulster University. Where any third party claim is made, whether or not legal proceedings are issued, arising out of or in connection with your right of access, you are required to co-operate fully with any investigation by this NHS organisation in connection with any such claim and to give all such assistance as may reasonably be required regarding the conduct of any legal proceedings.

You must act in accordance with Guy's and St Thomas's NHS Foundation Trust policies and procedures, which are available to you upon request, and the Research Governance Framework.

You are required to co-operate with Guy's and St Thomas's NHS Foundation Trust in discharging its duties under the Health and Safety at Work etc Act 1974 and other health and safety legislation and to take reasonable care for the health and safety of yourself and others while on Guy's and St Thomas's NHS Foundation Trust premises. You must observe the same standards of care and propriety in dealing with patients, staff, visitors, equipment and premises as is expected of any other

contract holder and you must act appropriately, responsibly and professionally at all times.

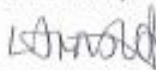
You are required to ensure that all information regarding patients or staff remains secure and *strictly confidential* at all times. You must ensure that you understand and comply with the requirements of the NHS Confidentiality Code of Practice (<http://www.dh.gov.uk/assetRoot/04/08/92/54/04089254.pdf>) and the Data Protection Act 1998. Furthermore you should be aware that under the Act, unauthorised disclosure of information is an offence and such disclosures may lead to prosecution. You should ensure that, where you are issued with an identity or security card, a bleep number, email or library account, keys or protective clothing, these are returned upon termination of this arrangement. Please also ensure that while on the premises you wear your ID badge at all times, or are able to prove your identity if challenged. Please note that this NHS organisation accepts no responsibility for damage to or loss of personal property.

We may terminate your right to attend at any time either by giving seven days' written notice to you or immediately without any notice if you are in breach of any of the terms or conditions described in this letter or if you commit any act that we reasonably consider to amount to serious misconduct or to be disruptive and/or prejudicial to the interests and/or business of this NHS organisation or if you are convicted of any criminal offence. Your substantive employer is responsible for your conduct during this research project and may in the circumstances described above instigate disciplinary action against you.

Guy's and St Thomas's NHS Foundation Trust will not indemnify you against any liability incurred as a result of any breach of confidentiality or breach of the Data Protection Act 1998. Any breach of the Data Protection Act 1998 may result in legal action against you and/or your substantive employer.

If your current role or involvement in research changes, or any of the information provided in your Research Passport changes, you must inform your employer through their normal procedures. You must also inform your nominated manager in this NHS organisation.

Yours sincerely,



Lauren Arnold
R&D Coordinator (non-commercial team)

Cc: HR department of Substantive Employer

From: [REDACTED]
Sent: 09 June 2017 14:18
To: [REDACTED]
Cc: [REDACTED]; R&D Business Finance
Subject: CCR4759, IRAS 216614, R&D confirmation of capability and capacity

Dear Dr Khoo,

CCR4759 Post Treatment for Prostate Cancer: The Psychosocial Needs of Black African and Black Caribbean Men and their Partners

The R&D Office has received all relevant documents and information and can confirm that the Trust has the capacity and capability to deliver the above study.

Please find attached the fully signed agreed Statement of Activities as confirmation. The study will be activated on the Hospital Information System (HIS).

The protocol will be uploaded in the Urology Section on the intranet, please let me know when you are ready to recruit and I will update the status.

With best wishes

[REDACTED]

[REDACTED]
 Clinical R&D Co-Ordinator
 Clinical Research & Development
 The Royal Marsden NHS Foundation Trust
 Tel 020 8661 3871

The ROYAL MARSDEN
 Life demands excellence

From: [REDACTED]
Sent: 09 June 2017 17:25
To: #Clinical Trials-Urology
Subject: FW: CCR4759, IRAS 216614, R&D confirmation of capability and capacity
Importance: High

Hi guys,

Please be aware the ULSTER study is now open.

It is a super easy study. Once a patient has been recruited the sponsor will conduct an interview with them, and that's it!

Attached is the protocol and any questions please ask either me or [REDACTED]

Thanks

[REDACTED]

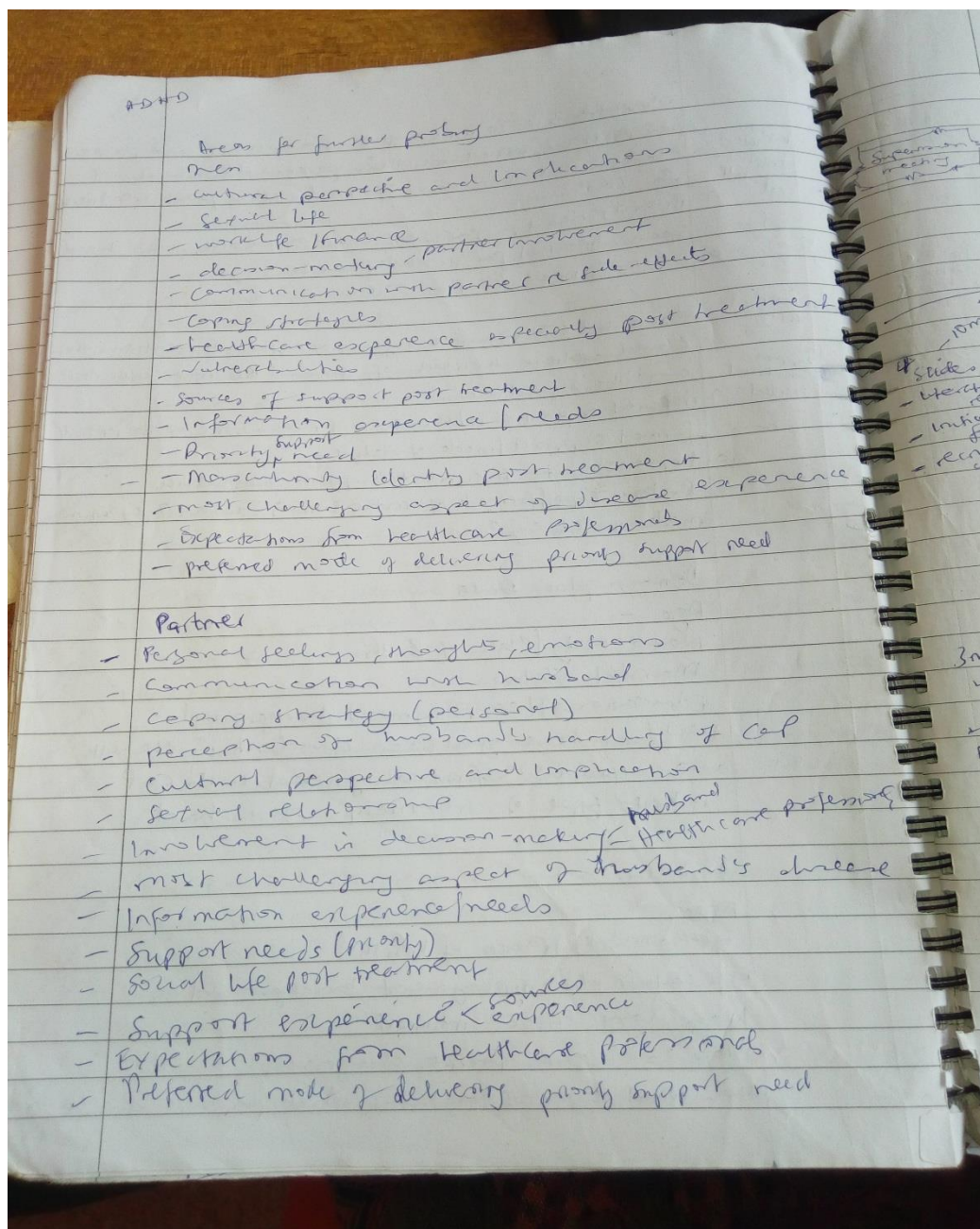
Appendix 11: Distress protocol

Distress protocol

In the event of a participant becoming upset during the interview, the researcher will follow the following procedure in dealing with such distress:

1. Stop the interview and allow participant to calm down
2. As a way of showing sensitivity to participant's distress, offer to reschedule the interview to another convenient date unless participant insist they have regained themselves and are happy to continue with interview.
3. If participant does not wish to reschedule nor continue the interview, thank the participant and request their consent to use their data collected up to that point.
4. If required, at the end of the interview, sign-post participant to available counselling services and advise them to speak to their GP or main healthcare provider.
5. Make a courtesy follow-up phone call to such participant a day or two later.

Appendix 12: Sample theme/category ideas to show the data analysis journey



Partners.

Objective &

Social Processes

Support Experience {

- husband getting diagnosed
- husband getting diagnosed } Disclosure
- waiting period
- Treatment
- Recovery
- life after treatment

Coping strategies

- Humour
- Keeping busy
- Showing optimism
- Religious faith
- focusing on day to day
- strong mental relationship

Priority needs for husband

- sexual recovery
- Information
- psychological support.

Priority needs

- Having somebody to talk to
- Getting rid of the cancer
- Needing psychological support
- Inclusive care (more service)
- Support groups (face to face).
- Information

mode of delivery

- face to face
- one to one -
- Personalised
- Online but personal contact details provided.

Pre-diagnosis
 Treatment
 getting checked
 diagnosis
 treatment
 decision making

experience attitudes reactions social processes priority needs solutions	physical psychological social (nuclear family) emotional religious experiences
marital relationship guarded communication submission pre-arranged withdrawal controlled emotions	coping focus on daily living family support responsible staying positive religious faith strong relationships expectations
social relationship selective communication network healthcare communications	controlled emotions guarded communication
Psychological uncertainty shock worry reassurance	Support at diagnosis
social process waiting guarded communication	priority needs - Impaired mental communication - Inadequate healthcare support
Physical & covered emotional Psychological Perceived need for nursing - reform physical services - reform mental services - enforce in future	getting checked diagnosis treatment priority needs post-diagnosis sexual health reproductive health support Psychological support Sexual counselling Partners support group - restored sexual intimacy

Treatment
 Best option
 Social needs
 Psychological

Aim 1: to explore the psychosocial needs after CaP treatment for BA and BC men and their partners resident in the UK and how best to address them.

Objective 1: to investigate the experiences of BA and BC men with CaP; and where applicable also the experiences of their partners respectively. Emerging Themes

Men	Partners
Cultural threat to men's masculinity – <ul style="list-style-type: none"> • Not meeting financial obligations, • Reduced physical activity • sexual dysfunction 	Feelings of isolation and exclusion <ul style="list-style-type: none"> • Men as leaders in decision-making • HCPs not involving partner in discussions • Having unanswered questions
Sexual challenges significant and ignored by HCPs	Partners needs not recognised <ul style="list-style-type: none"> • Stress • Anxiety and worry • Information needs • communication • support needs • sexual needs
Men as leaders in decision-making	Care-giver burden
Belief that Jesus will heal them and preference for traditional healing remedies delayed accepting treatment	Challenges in marital communication
Incontinence and fatigue, threats to work life	
Limited public disclosure of Prostate cancer – masculinity ego <ul style="list-style-type: none"> • not wanting to be pitied or admit vulnerability self- stigma • spiritual reasons 	Coping strategies <ul style="list-style-type: none"> • Personal faith • Prayer • Exercise • Keeping a diary
Coping strategies <ul style="list-style-type: none"> • Personal faith • Prayer • Reassurance in having had children • Resilience • Partner support • Peer support • Physical activity – exercises 	

Objective 2: to examine men and partners' respective perceptions of support care after CaP treatment

Men	Partners
Fairly wide Support network - Partners, HCPs, family, friends	Very limited support network - due to husband's decision not to disclose
Mixed perceptions of healthcare support – positive and negative	Family and friends (where disclosed) very supportive

Positive healthcare experience <ul style="list-style-type: none"> • successful treatment procedure • being given options re treatment choices having caring and supportive HCPS 	Disappointment at partner information needs neither being acknowledged nor met by men and HCPs
<ul style="list-style-type: none"> • Negative healthcare experience • disappointment at information needs not being met • Anger at diagnosis not been picked up earlier 	

Objective 3: to investigate from men and partner's perspectives, what are their perceived individual needs and the needs of each other post-treatment for CaP

Men	Partners
Psychosocial support for sexual recovery <ul style="list-style-type: none"> • information, • aids, • peer support 	Improving Marital communication <ul style="list-style-type: none"> • to deal with isolation and exclusion • to relieve anxiety and worry • Emotional healing
Regaining physical fitness – to ensure continued physical; activity and work	Psychosocial support for sexual recovery <ul style="list-style-type: none"> • information, • aids, • support from HCPs and other survivors

Objective 4: to investigate what health professionals perceive as the needs for BA and BC men post-treatment for CaP

- Increased education and awareness on prostate cancer within the Black community to improve their help-seeking behaviour
- Partner inclusion/engagement in men's care pathway

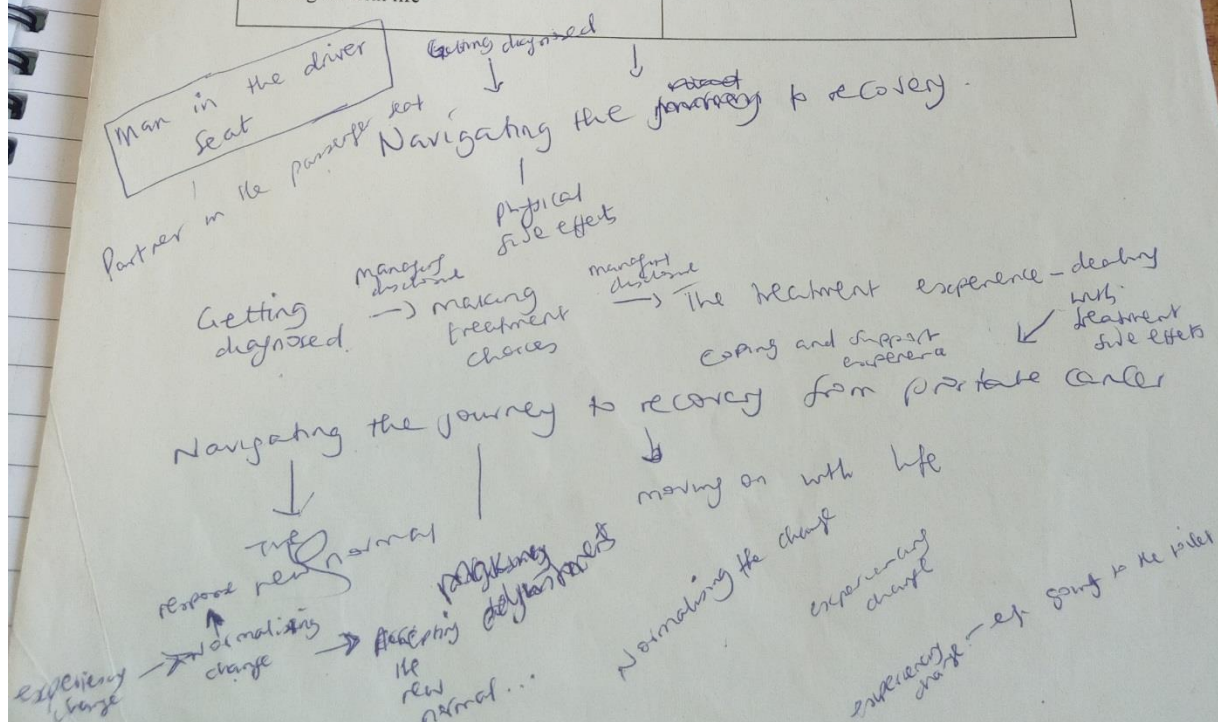
Objective 5: to examine suggestions for interventions that could address the needs of BA and BC men with CaP and their partners

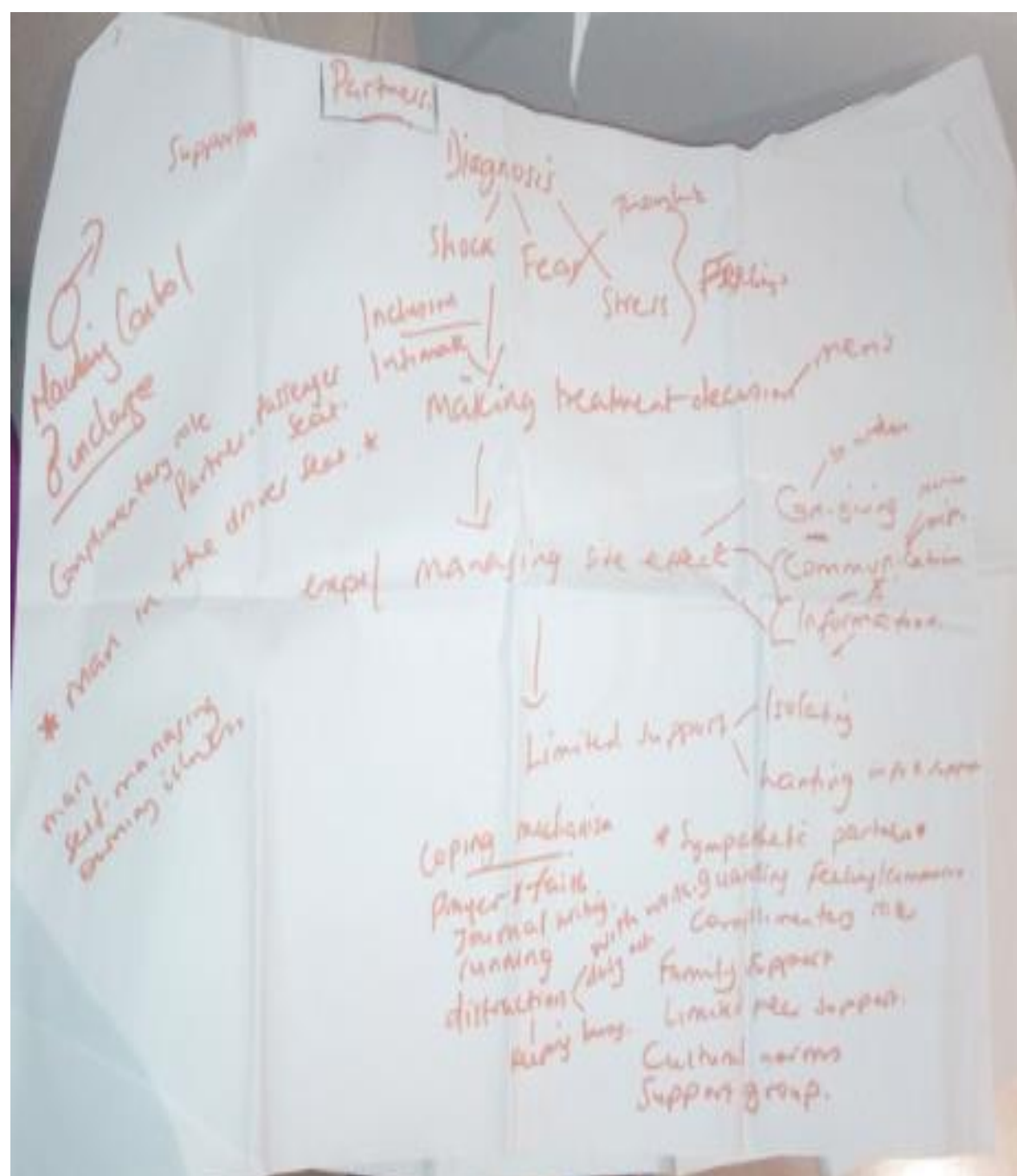
Men	Partners
Information	Factual information <ul style="list-style-type: none"> • to help partners better understand their men's feelings • how to support them better • couple counselling to improve marital communication and deal with sexual challenges
Constant access to dedicated healthcare professionals to address their psychological concerns	Constant access to dedicated healthcare professionals to address their psychological concerns
Incorporating prayer and faith in psychosocial support offered	Support group to associate with other partners and get peer advice and

HCPs to 'respect' Black men and avoid stereotyping Peer support delivered through <ul style="list-style-type: none"> • group setting, • stalls at social events such as park parties, • one-to-one buddy 	
--	--

Aim 2: Basic social processes in relation to inform theory development:

Men	Partners
Getting diagnosed	Accepting partner's diagnosis
Making treatment choices	Dealing with personal psychological concerns
Managing disclosure about diagnosis - cultural beliefs and ideas	Maintaining normalcy
Experiencing and dealing with treatment side effects	Providing support and care
Navigating the psychological journey - cultural beliefs and ideas	Experiencing care-giver burden - worry, isolation, exclusion, stress
Coping with prostate cancer	Navigating changes to marital relationship - sex life, partner's withdrawal/depression/mood swings
Support network and experiences	Craving for communication
Adjusting to the new life - sex life, work life, social life, finance, masculine identity	Accessing support
The road to recovery	Feeling relieved
The new normal	
Moving on with life	





Literature review —

You must report all your findings
Do I need this? To make the thesis comprehensive

Plan on what to cover within the thesis
decide what needs to go into the paper

✓ needs to come into the remaining
the — make reference to the papers.

memory — rationale

10 February 2018. — with Kells
Colleague.

unrecognized co-victim of prostate cancer

Testing

ownership

children in the back seat
(protecting them
from the sadness)

logical. in emotional
taking the leadership

logical vs emotional
in control / management

respect

protection
responsible.

Responsibility. Car
the car. for everyone

decides the route. / final
destination.

loneliness
journey

Front seat passenger has responsibilities

expectations for the passenger to be

involved in the journey

Passenger may not be happy with the direction of the
journey but still follows through because no choice

driver not wanting to talk to avoid distractions, or
being told what to do

wife in the back seat seen as role to be with
children as her priority and not him as the

priority.

Head of the family

prakti hold-
up

up- /
bad weather
unavoidable

The diseases (car) is inevitable } threatens
reactions to the inevitable } fated } the driver.
 and ^{needs}

reactions to the workable
Panic
accept

Fate d

strong family

mental content at a time

Healthcare
Social - Ch. 10 & 11

peer influence

our determination to
ability to
institutions - front

merge to? back-

1) Parmer Henry Res

total environment

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↓ new ↓
↓ use ↓

capitales / unavoluntaria

9 Subject) Fated ✓

Know

Support	Past experience
---------	-----------------

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20/10/2010

11/11/11

5

Appendix 13: Sample extract from reflective memo

Managing disclosure

Reasons for limited disclosure in many cases was to avoid stigma, not wanting to be pitied, spiritual connotations and only disclosing to those who **only need to know**. What is stigma? Stigma from who and why? Masculinity ego? Cancer stigma remains a big issue among these populations despite their increasing education and social exposure as most people perceive being diagnosed with cancer as inevitable death, almost immediate death, where they may then be perceived them as 'walking corpses'. Further investigating reasons for limited disclosure among Black men, it appears superstitious beliefs re witchcraft, spiritual influences which is common in the African culture made some men to withhold info regarding their illness. I had thought reluctance to disclose was more of a BA thing than a BC thing, as few of the BC men interviewed earlier seemed to be open towards disclosure... until I interviewed more BC Men. For example, during his interview, Larry (pseudonym) noted his BC friends were more secretive about their diagnosis and he didn't quite know until he started sharing his diagnosis. Even after sharing his own diagnosis, some of his friends who had been diagnosed with same CaP were still very reluctant to share their disease experience with him. He also gave an example of his uncle getting upset with his mum because she disclosed her mother's cancer diagnosis with her friends. It was meant to be a 'secret'!

The procedures especially the DRE and biopsy also seem to add to some men's reluctance to share their prostate cancer diagnosis/experiences. Could it be that they will be looked down upon if no longer able to perform some functions after treatment? For example sexual performance and procreation? Who will look down on them? If stigma was not voiced by those people, could this be more of self-stigma than social stigma? Similar to how some people experience inferiority complex and feelings of inadequacy even when nobody has said they are not adequate?? Obviously their partners are more supportive than despising, the men also mentioned that employers and friends were also supportive and sympathetic to their cause, so why feelings of being stigmatised?? 'maybe more to do with fatalistic beliefs regarding cancer in which case society's focus is less on the side effects of treatment and more on the perceived eventual outcome of the diagnosis (death). Perhaps it may also be the stigma related to a compromised sexuality which defines their masculinity?? Calls for increased education and awareness, which is part of what the men are also advocating for.

Thinking further on the negative perceptions of sickness disclosure common among Black people, I think there may be some indications of self-stigma rather than social stigma for cancer among these men themselves. I also think that whilst the social response to men's diagnosis is usually more of sympathy and support (based on all study participants' narratives so far), perhaps men who are reluctant to disclose their illness feel inadequate in themselves as their 'masculinity ideals' may have been compromised by treatment side effects' especially sexual dysfunction and incontinence problems??. Maybe some also see disclosure or discussing their illness as a sign of admitting their vulnerability which does not conform to the traditional masculinity norms commonly upheld within their cultural community??? For men who seemed more open towards disclosure, why? Their socio-demographics (e.g. cultural background, age range, socioeconomic status, marital status) were very similar to that of men who avoided disclosure, which makes the issue of disclosure even more complex to understand among these men. What seemed obvious though was that for those who readily disclosed, they viewed it as their own coping strategy, especially when providing advice and mentoring to others. Every individual has his own unique way of viewing the CaP experience and dealing with it! Can a 'one size fit all' support work for this culturally similar group? Need to find out more!!

Appendix 14: Sample field note

Face-to-face interview with Mr Dave (Pseudonym) on Friday 26th May 2017

Field note

Mr Dave (pseudonym) was a 62-year old man who originated from [REDACTED] and had been treated for CaP in 2015 with Brachytherapy (22 months ago). Dave was very open in sharing his experience with me in a very articulate manner. My earlier conversations with him over the phone (to discuss the research) and shared ethnicity as a 'fellow BA' also seemed to have promoted rapport. His priority for treatment choice was the desire to preserve his prostate and remain sterile in the face of a potentially debilitating disease. He had very strong views about his sexual virility and a decline in his sexual prowess prompted him to seek help in the first instance before his diagnosis was later confirmed as CaP. He mentioned that being sexually potent and virile makes a real man within his African context, and that fatherhood was a treasured cultural value for him as an African man.

His perception of cancer stigma influenced Mr Dave's decision to strictly limit disclosure of his CaP illness within closest family only (partner, brother, first son, employer). He admitted being psychologically affected by his CaP diagnosis mostly because cancer is often regarded as synonymous with death. He noted he had to be strong and deal with the situation. Prior to considering treatment options offered by his doctor, Mr Dave sought information personally by asking friends in the medical field and also going online to aid his decision-making by himself, no partner involvement, even though he has a partner (unmarried). Mr Dave was so keen to keep his diagnosis private that he coded his enquiries from his medical friends so they will not know he was seeking the information for himself. Interesting! Mr Dave further attributed his reluctance towards disclosure to a desire to retain control over his personal information.

His main coping strategies were his spirituality (which he demonstrated through prayers and faith), information through self-researching, staying positive, resilience. Dave unabashedly described his experiences giving necessary details re how his sexual life was impacted and how he navigated that aspect after treatment. Dave mentioned being in an open relationship in which himself and his partner of 10 years were not obliged to remain loyal to each other. Dave strongly opined that it was his positive thinking nature that enhanced his coping with the CaP illness and this made him to think of creative ways to deal with his sexual problem and urine incontinence, by himself regardless of what was provided by his healthcare team. He sounded averse to counselling as he portrayed a sense of being able to deal with things by himself. Machoism?? He was of the opinion that healthcare professionals can only provide 'theoretical' support due to them not having undergone the practical aspects of the CaP. Hence, he insisted on men taking ownership for their illness in terms of seeking help and support if and when necessary. Interesting to hear this as two men previously interviewed wanted HCPs to be proactive in providing support especially information to deal with treatment side effects!

Mr Dave demonstrated positive disposition which raises question around mental health and coping with treatment side effects of prostate cancer??? Resilience? Mr Dave works as [REDACTED] in an NHS hospital and noted he has no expectation from healthcare professionals but suggests that individual patients to take the lead regarding their care. Possibly because of his background and self-reliance, other men with more expectations may need more proactive support from HCPs? Stigma prevented Mr Dave from further disclosure. What is it about this stigma in an ever changing world? What is it that makes use of clinical aids for sexual performance and urinary issues less desirable? Dave said he just wanted 'to be normal' What does it mean to be normal with a debilitating illness? Is it possible to really achieve that normalcy?? Maybe there may be a need to redefine what it means to be normal post treatment compared with pre-treatment? How do survivors negotiate the inevitable changes brought about by treatment side-effects and still 'be normal'??

Appendix 15: Sample extract from theoretical memo

Emerging theory – ‘Man in the Driver Seat’

There are variations in the definitions of a theory depending on the philosophical and epistemological perspectives from which such is viewed e.g. either objectivist or social-constructionist. But noting my interpretivism philosophical perspective and social constructionist epistemological stance and the aim of this research, I will use the definition provided by Thornberg and Charmaz (2012): *a theory helps us to understand the relationships between abstract concepts emerging from this research in order to address the ‘why’ questions.* The substantive theory developed in this research could potentially help to address the ‘why’ question in relation to the experiences of BA/BC men and their partners after CaP treatment. Emerging categories from the three sets of participants in this study showed that: the men preferred to self-manage their illness and treatment side-effects while partners were almost ‘pushed’ aside; men did not engage their wives very much in the decision-making and where they did, it was at their own prerogative; the men regulated information and communication with their partners, majority of whom felt excluded and isolated; men controlled disease disclosure which impacted on their own support experience and that of their partners as the majority did not disclose to the wider people in their society; the men decided when to get treated and which treatment type to have within the options provided by their doctors and after making personal research and consultations. All seemed to have been influenced by the men’s perceptions of their cultural roles and identities within their BA/BC cultural context and a resistance to allow the CaP to strip them of those roles and identities. Majority of the narratives from the men, partners and HCPs all attested to this gendered definition of masculine role and identity within the BA and BC cultural contexts and this could be seen to have significantly shaped both the men and their partners’ experiences.

I had pondered again and again over the theory wondering whether it is comprehensive enough to clearly understand the experiences of my participants and if the cultural element is well captured without bias. I was also careful not to allow my shared ethnicity and similarities (married female) with study participants to influence my interpretation of what was happening in the data. To deal with these concerns/potential bias, this theory was co-constructed with my supervisors through interactions, discussions on emerging categories from each sample group as data analysis progressed. I further triangulated the emerging theory with two independent colleagues (n=2) from other cultures and who were not part of the research to challenge and/or validate some of my assumptions. My colleagues spontaneously interpreted the emerging theory to reflect the narratives and experiences of my study participants even though they were not involved in the data collection process and had not seen any of the transcripts nor had prior discussions on the data. This provided a sense of validation and helped to increase my theoretical sensitivity towards the emerging theory and enhance its credibility and trustworthiness.

We firstly deconstructed ‘man in the driver seat’ into its different component entities to aid delineation of the concept and validate its usefulness as a practical metaphor which credibly reflects my data. Subsequently, these components were re-constructed with the embedded meanings in participants’ own narratives. For example, the driver seat was perceived as the power structure within the BA/BC context in relation to marriage, illnesses, decisions etc. Oftentimes, the context determines who occupies the driver seat as this could vary across cultures, gender, socio-economic status and other external regulations. Narratives from men and partners in this study indicated that within the BA and BC cultural contexts, the ‘driver seat’ is where men are culturally placed within the society both within the marital setting and in the wider society. There appears to be a hierarchy of power in which the men are dominantly placed in the driver seat having leadership roles and responsibilities, whilst the woman often occupied a subordinate position in the passenger seat either as a front or back-seat passenger depending on individual circumstances. Such cultural dictates regarding men’s and women’s roles and identities were seen to shape how BA and BC men and their partners responded and coped with CaP. This rang true for majority of participants in this study in which the role of the man as the head of the family, breadwinner, leader in decision-making and sexual relationship was significantly highlighted by men and partners. As one partner mentioned “...he is the strong male of the family, he is the head of the family, and he is the breadwinner...” So there was a consensual acknowledgement across the study participants that the driver seat is ideally occupied by the man within the BA and BC cultural contexts. Whilst not all the men claimed to be ‘self-sufficient’, they unanimously exhibited a sense of control over key aspects of their prostate cancer course. There were

descriptions of men owning the illness as explained by one partner "...he very much owned his illness and didn't want to share..." and admitting sole responsibility as mentioned by one HCP "...he said 'I don't want my wife to know' I said why maybe they have concerns for their wives, he said 'my wife has got high blood pressure and if she gets to know, it's going to make it worse'..." (HCP 6, Uro-Oncology Nurse).

The driver was also perceived as having control regarding the routes and final destination of the car as clearly articulated by one partner that "he knows his body, he knows where he wants to go with this..." Being in control and in charge also articulates the leadership expectations and role of the man as the 'driver' as he is expected to know how to drive (lead), make logical decisions not controlled by emotions (another gender difference between men and women as we identified men are more logical but women are emotional?). This may explain why many men in this study were more factual than emotional, their concerns were more psychological than emotional! To make logical decisions, the driver needs concentration and focus which, depending on his personality can sometimes mean that talking to passengers might be a lesser priority, for him, as some women expressed frustration that their husbands neither recognised their needs "...It might not have occurred to him that this woman that is taking care of me has some emotional needs as well..." nor shared their 'emotional' priority concerns for improved marital communications "...I tell him all the time about communication but it's a big issue..."

The self-driven and autonomous behaviour of the men as was also highlighted by the HCPs "...it struck me that actually we get a relatively high proportion of young black men who are offered the chance of cure, who disappear..."; partners "culturally, Black men do not like to be told what to do, because they tell people what to do..."; and men themselves "...I think it was my decision first, it was my decision primarily and then she backed me up, it wasn't as if I sat down and said these are all the various options, I said there are all these various things but this is what I'm going to do... being the only son and growing up without a father you learn to take decisions, I lead even at work, so I'm quite, some people say I find it quite difficult to delegate..."

Although often overlooked due to the stereotypical portrayal of men as strong and tenacious, it is important to recognise that being in the driver seat can also be isolating, exhausting and physically and mentally tiring due to the various physical (the driving activity e.g. physical side effects of CaP) and mental (thinking for self, passengers (e.g. family's financial welfare), routes, traffic laws, destination etc.) responsibilities and expectations placed on the man. As articulated by one man: "...I was scared erm I'm a very practical man erm and I'm also the breadwinner, so my family is very reliant on me in terms of you know financial well-being, I've got erm you know, I've got a 21 year old daughter and a 16-year old daughter and my wife and like I said I'm the breadwinner, I was scared for them I was saying then how do I make provisions for them, what's the next steps?..." which suggest that men and leaders have need and need to be supported as well. Such physical and mental 'exhaustions' can be minimised for the driver by the passengers (e.g. to provide companionship) in this case wives, who were providing practical and emotional support for the men for which majority of the men were full of praises for how much their partners were very supportive and how that has helped them on the journey "...my wife has been extremely supportive, she goes with me to all my check ups and things and all my follow up and things... when she thinks I am being down, she will encourage me and things like that...". Although the driver may feel exhausted and need help, he still has to make the decisions on whether he wants to accept the support or not, which further seem to explain why the men had varying views regarding disclosure and accessing of support.

Appendix 16: Sample audit trail of key methodological decisions and actions



Ulster University
Faculty of Life and Health Sciences
School of Nursing

Record of Meeting between Research Student and Supervisor/s
 This form should be completed jointly by the research student and supervisors/s at
 the conclusion of each meeting)

1. **Name of Research Student**
(BLOCK LETTER) MRS OLUFIKAYO BAMIDELE
Name of Supervisor/s
(BLOCK LETTER) PROFESSOR EILIS MCCAUGHAN, DR HELEN MCGARVEY
 AND DR BRIEGE M LAGAN
2. **Date of Meeting:** 9th November 2016 3. **Duration of Meeting:** 1hr
4. **Issues discussed (Please List)**
 - Feedback from Seminar 2:
 - Link aim and objectives to grounded theory and specify who the focus of theory is?
 - adding survey element/mixed methods
 - Interview of Participant 1 (Man with Prostate Cancer)
 - Good in-depth interview although interviewee tended to generalise in
 - Some issues/experiences could be explored more further e.g. incontinence, sexual impact, exploring more in-depth e.g. issues, side effects – how these impact on life; role of partner, sexual journey, journey of needs, content of discussion with partner, how long since in relationship with partner
 - For subsequent interviews, focus more on aim and objectives of study and interview guide. Avoid triple and double barrel questions, Question on why participated and why some don't participate in research
 - Update on Recruitment
 - Radio stations – no response
 - Potential applicants from Barts Hospital
 - ? extend sample to health professionals – Eilis has contact at Royal Marsden ' ' urology nurses
 - Ethics - IRAS application
 - Sent to Dr ' ' 08/10/16 for peer review – after discussion put on hold until health professionals included in application – Helen to contact
 - To now amend and include health professionals and Royal Marsden Hospital
 - Papers
 - Literature review – no response back from Journal as yet
 - Recruitment
 - Methodology Chapter – to update and then resend to supervisors for comments
5. **Suggested further work (Please List)**
 - Send exploratory email to ' ' re recruitment of patients and HCPs through Royal Marsden Hospital



- Amend IRAS submission to include health professionals and recruitment from Royal Marsden
 - Continue with interviews
 - Review Methodology chapter
 - Plan paper on recruitment
 - Helen to contact [redacted] to retrieve IRAs form
6. Are risk assessments for this project fully up to date? Yes ☒ No ☐
7. Date of next meeting: Monday 5th December 2016 (UUJ) 14:30
8. Signature of Research Student *Olufemi Ayo Banichele*
- Signature of Supervisor/s *Helen McQuinn, Briege H. Lagan*

Date: 9th November 2016

IMPORTANT INSTRUCTIONS: *One copy to be returned to Research Graduate School*
One copy to be retained by supervisor
One copy to be retained by student

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